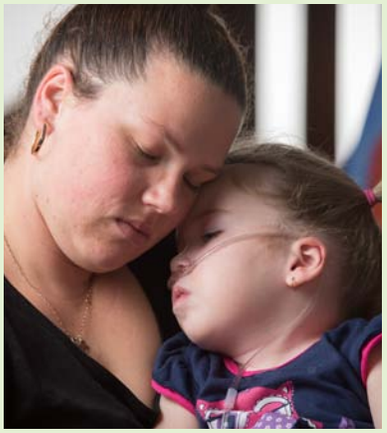
Hidden Lives, Hidden Patients



2015

World Hospice & Palliative Care Day Report

HIDDEN LIVES, HIDDEN PATIENTS

World hospice & palliative care day

10 October 2015

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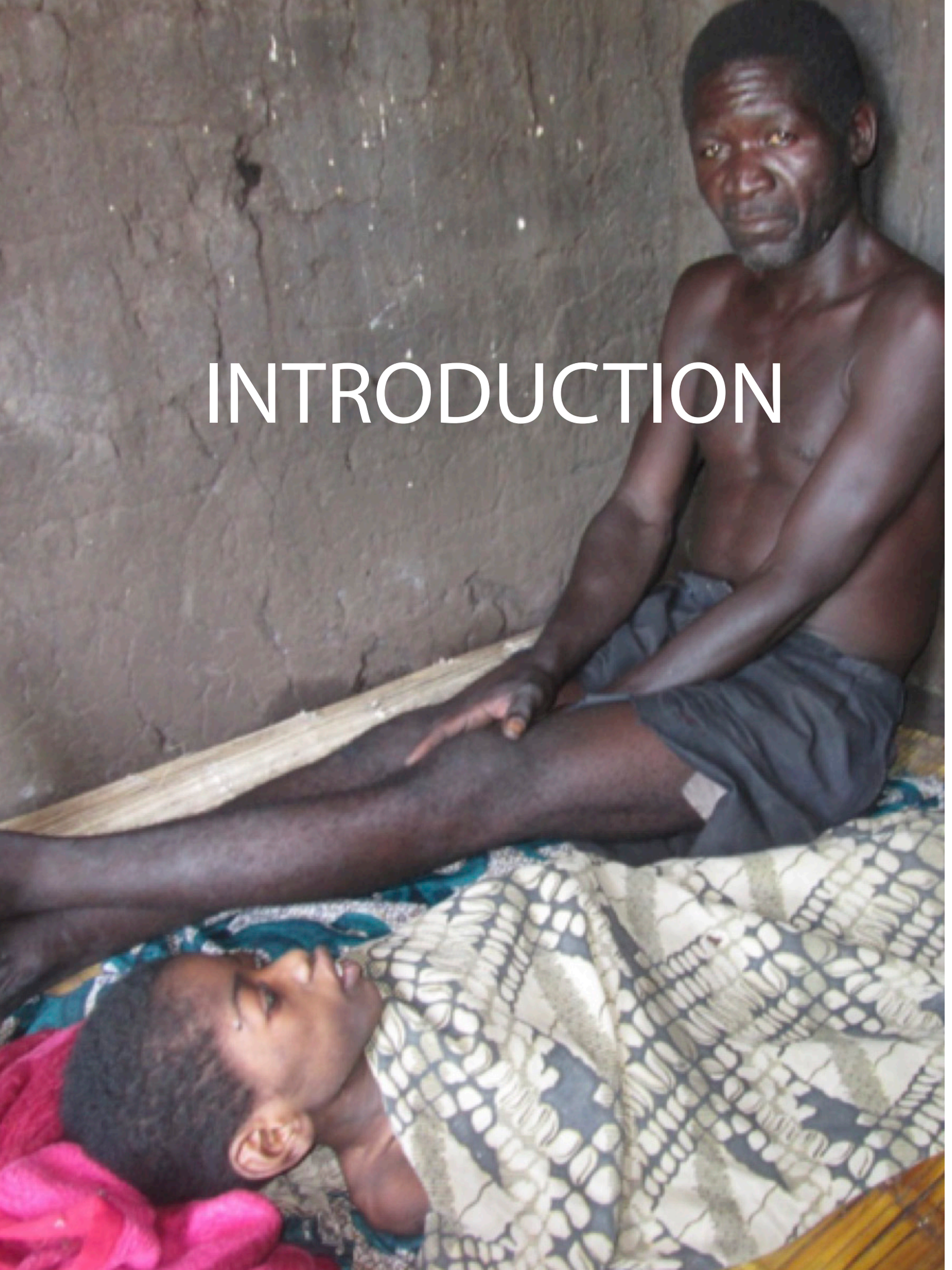


INTRODUCTION

Introduction

"Palliative care services need to be provided in accordance with the principles of universal health coverage. All people, without discrimination, should have access to nationally determined sets of basic health promotion, preventitive, curative, rehabilitative and palliative health services and essential, safe, affordable, effective and good-quality medicines and diagnostics."

WHA 2014 [3]

The vision of the Worldwide Hospice Palliative Care Alliance is a world with universal access to hospice and palliative care and it hopes to achieve this through fostering, promoting and influencing the delivery of affordable, quality palliative care throughout the world. However, a study looking at the status of palliative care in 234 countries found that 42% had no delivery system for palliative care services and in 32%, service delivery reached only a small percentage of the population. Palliative care was integrated into health care systems in only 20 out of the 234 countries (8.5%)[1]. Access to palliative care medications is also a challenge, with around 80% of the population lacking adequate access to the medications needed for palliative care. In 2010 the WHO reported that 66% of the population had virtually no consumption of strong opioids and only 7.5% of the population live in countries considered to have adequate opioid consumption levels [2].

Palliative care should be available for all with life-limiting illnesses, regardless of age, race, disease, gender, sexuality, or where they live, yet there are many people for whom access to palliative care is still only a dream. Some of these fit into the 'traditional' groups of people for whom palliative care services are provided, yet others are more 'hidden', they are 'patients' for whom access to palliative care is even harder to access, and for some, the need may not be recognised, and will be different in different parts of the world. Thus there are 'hidden patients' with 'hidden lives'. It is some of these hidden patients that we hope to highlight through this World Hospice and Palliative Care Day report, such that their needs may be recognised and no longer hidden.

The report has been split into two sections: Part 1 highlights the needs of children as globally, children are often neglected and 'hidden', and Part 2 highlights the need for palliative care in a wide variety of other important groups such as young adults, individuals with HIV, psychiatric illnesses etc. The list is not exhaustive and does not cover all hidden groups, but gives examples of programmes meeting such need, other hidden groups, such as those with disabilities, and injecting drug users, have been covered in the 2010 World Hospice and Palliative Care Day report on Sharing the Care.

"Both the Worldwide Hospice Palliative Care Alliance (WHPCA) and the International Children's Palliative Care Network (ICPCN) are working towards improving access to hospice and palliative care worldwide.

Advocacy tools like this report help make your case. World Hospice and Palliatve Care Day creates tools to advance awareness of best practices and global needs. Please join the movement to advance hospice palliative care worldwide."

Sharon Baxter

ED - Canadian Hospice and Palliative Care Association

Chair - Advocacy Committee WHPCA and ICPCN Board Member

We hope that this report will provide a voice for our patients, their carers and local hospice and palliative care services, which can be used when advocating for services for these 'hidden patients' within our own countries. A lack of awareness, understanding and commitment at the national and international levels are some of the major barriers to hospice and palliative care. We need supportive national and international organisations, government commitment, access to services including to medications for pain treatment, and a passion to create change. The voice of those involved in providing such services is therefore key in bringing this about [(4)].

Thus we hope that this report will be useful to you as you advocate for the development of services in your own community, district, country or region. By providing case studies, along with a few key facts for the provision of palliative care for different 'hidden groups' we hope that you can take these case studies to key stakeholders and organisations within your community and use them to advocate for similar services. Leading up to the publication of this report for World Hospice and Palliative Care Day, the WHPCA and ICPCN have developed some key messages as part of a charge to action to the development of services for all, such that these 'hidden patients' will be able to access care in the future. Please use these key messages and the call to action alongside this report to advocate for the services as needed.

What is palliative care?

"The goal of palliative care is to improve the quality of life for people and family members affected by life-threatening illness. It is not limited to those suffering from specific diseases or only encompass care of the dying… the WHO definition of palliative care emphasises the focus on active living…. the provision of palliative care has to be adapted to the country, culture and context."

WHPCA[7]

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual[5]. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care for children represents a special, albeit closely related field to adult palliative care and is the active total care of the child's body, mind and spirit, and also involves giving support to the family[6].

PART ONE:
Children

The global need for palliative care for children

"Access to palliative care for children is poor in many parts of the world. Whilst acknowledging that in some developed countries, children's palliative care is well developed, in the majority of countries this is not the case. Therefore it is essential that we continue to advocate for the development of children's palliative care globally."

Joan Marston
CEO
ICPCN

Previous estimations on the need for palliative care for children have been based either on mortality or on using data from the United Kingdom to estimate a global figure, however both have limitations. To gain a better picture of the global need, the International Children's Palliative Care Network (ICPCN) and UNICEF carried out research in South Africa, Kenya and Zimbabwe into the need and coverage of children's palliative care services in 2013. Results show the need in developing countries is considerably higher than in a developed country and access to children's palliative care was low in all three countries - less than 1% in Kenya and less than 5% in South Africa and Zimbabwe.

This research is ongoing in other countries. The ICPCN estimates that the global need for general palliative care for children will be at least 20 million and at least 8 million for specialised services. As only 66 countries have any specialised palliative care services ICPCN estimates that globally less than 1% of children with life-limiting conditions are receiving palliative care.

There are a number of barriers to children accessing palliative care services. Lack of trained health care workers and resources is often quoted, yet Malawi, which is a low-income country has well-developed programmes and a number of trained health care workers. In the experience of the ICPCN, a dedicated and committed leader in a country can develop children's palliative care to a high standard, even when resources are limited.

- 6% of all people in need of palliative care at the end of life are children. [8]
- The estimated number of children globally in need of palliative care at the end of life is 1.2 million [8] with another 19 million estimated as needing a palliative care approach [9].
- There is a big gap between need and provision of services, for example, in Zimbabwe 180:10,000 children need palliative care, and less than 5% are receiving care.[10]
- The greatest need is seen in the African, Eastern Mediterranean and South Asian regions.[8]

Perinatal and neonatal palliative care in Argentina

"Perinatal palliative care is the planning and provision of supportive care during life and end-of-life care for a fetus. Newborn infant or infant and their family."

British Association of Perinatal Medicine [15]

The Hospital Nacional 'Profesor Alejandro Posadas' (HNAP) is a tertiary health-care institution located in the suburbs of Buenos Aires, Argentina. The paediatric palliative care team (PPCT) was created in 1996 and in 2006 its objectives were redefined to include children with non-malignant conditions. Palliative care for newborns is still a developing area in HNAP, and although the staff are able to identify those needing palliative care, more often parental agreement determines whether a palliative care transition takes place, and so curative technological efforts often continue regardless of neonatal physiological conditions. This situation is, however, being slowly modified through collaboration between the Neonatology Department and the PPCT.

During the past year a new challenge appeared for the PPCT. The emerging problems resulting from the scientific and technological advances in obstetrics, raise questions about the opportunity to incorporate palliative care for conditions that threaten the life of the fetus, minimising situations of physical and emotional suffering. Following the early detection of genetic diseases and complex malformations that endanger the viability of the fetus, the Obstetric Department of HNAP began to address these issues from an interdisciplinary perspective, with neonatologists, geneticists, paediatric cardiologists, obstetricians and the PPCT. Antenatal interventions include communication-related aspects, emotional support for the mother, and support for decision making before and after childbirth. Since the PPCT began to get involved last year, they have been able to help 25 families.

- More children die in the perinatal and neonatal period than at any other time in childhood [11], with most deaths occurring within the first 27 days [12].
- In comparison with adults, a greater proportion of children who die in hospital do so within the intensive care unit[13], many of which are in the neonatal intensive care unit
- Despite advocacy for parental choice in where palliative care is delivered, home and hospice is only considered in a small number of neonates [14].

Alex Gomes © 2011 Touching Rainbows ICPCN

POSADAS HOSPITAL NACIONAL

Palliative care for children with Cerebral Palsy in India

"Since the palliative care project has been set up at Jawhar we have seen the quality of life for these children with cerebral palsy improving, along with that of their families. Provision of palliative care to children with cerebral palsy is essential and we need to do more to make this a reality across India."

Prof. Maryann Muckaden
Tata Memorial Hospital
Mumbai, India

The 'Children's Palliative Care (CPC) Project' of the Indian Association of Palliative Care (IAPC) began its journey in Maharashtra, India, in October 2010, with a view to address the needs of children with life limiting conditions such as HIV/AIDS, Cancer, Cerebral palsy, Thalassemia and other conditions. The main aim was to create a child friendly environment where children are not threatened with the illness that they face; especially where poverty, illiteracy, superstitious beliefs, gender differences and social stigmatisation may be an integral part of their every-day life. It aimed to set up three model sites providing Children's Palliative Care in Maharashtra, and during the development of the site at Jawhar, we identified around 100 children with cerebral palsy (CP). In some families there was more than one child suffering with the same condition.

Palliative care provision for the children with CP has included physiotherapy, the use of communication devices, bracing, speech therapy, medication to relieve painful muscles, and counselling. Some of the lessons learnt in the provision of palliative care for children with CP include the need for a multidisciplinary team, with a physiotherapist, occupational therapist and speech therapists being core members of the team. The need for support groups to empower carers and networking with the government to provide essential services. The need for palliative care for the large number of children in India with CP is great and steps are being made to extend such service provision to other parts of the country.

- The overall prevalence of CP worldwide is 2.11 per 1,000 live births [16].
- CP includes a mixed group of early-onset, non-progressive, neuromotor disorders that affect the developing foetal or infant brain [17].
- 28% of children with CP have epilepsy, 58% communication problems, 42% vision problems and 23-56% have learning disabilities [18].
- 80% of children with disabilities live in resource-poor settings, however rates of CP and neurological impairment are difficult to obtain in these settings and treatment options limited [19].

Palliative care for abandoned children in China

"I have been privileged to witness the most amazing love – from women in this country who have been raised in a man's world, coming into their own, giving loving cuddles, smiles and play to the most 'difficult' children because they have learned to see the child, not the illness. We have tried to build a culture in the Butterfly Homes which cares for the individual - with people who have been raised in the communist system."

Lyn Gould
Butterfly Children's Hospices

Butterfly Children's Hospices (BCH) established the first children's hospice and community palliative care service in China. They are working in co-operation with the Chinese government to establish a model of children's hospice and palliative care that is sustainable, promoting the concept that every life is valuable and a gift. Butterfly Homes are located in government run orphanages and provide care for abandoned babies and children that the doctors estimate have less than six months to live.

The abandoned, dying children which BCH look after have many different forms of illness and/or disability ranging from simple prematurity to complex genetic disorders that lead to an early death. In between, the majority are those conditions caused by ignorance and poor healthcare, such as syndromes caused by perinatal maternal viral infections, which lead to chronic and often severe disability. Providing palliative care for children can be complex in a superstitious culture where having a sick or disabled child is viewed as a curse on the family and a punishment for wrongdoing or ancestor neglect, often leading to abandonment. Families will often abandon their child in desperation, not knowing what else to do and hoping they might get the care they need in an orphanage.

Isabel was born with serious liver disease, and was sent to Butterfly Home for palliative care at 4 months of age. At first she was tense and afraid to be touched but during the two years she lived at BH she relaxed and learnt to trust – she was able to live a happy, active life. Her time on earth was short but every day was truly cherished.

- In July 2014 there were 1,355,692,576 people living in China, with 17% being under the age of 15 [20].
- Infant mortality in China is 14.79 per 1,000 live births [20].
- The 'family planning' or 'one child' policy was introduced in 1978 to alleviate social, economic and environmental problems in China, although this has been relaxed in recent years and families with children with disabilities are allowed to have more children [21,22].
- An estimated 10,000 children are abandoned in China every year [23].

Butterfly Children's Hospices

Palliative care for children with genetic conditions in Singapore

"Genetic conditions, particularly when severe, can wreak havoc not only to the well-being of the young child but also almost every other member of the family, with uncertain, yet ominous implications on subsequent pregnancies. The tremendous burden is multiplied when more than one child is affected by the same syndrome. These families certainly deserve the comprehensive and compassionate support that palliative care can provide, to make every moment meaningful and worthwhile."

Dr Poh Heng Chong
StarPALS

- 2-3% of births result in babies with either congenital or genetically-determined abnormalities [24].
- Duchenne muscular dystrophy affects approximately 1 in every 3,500 male births in the UK [25].
- Many children, particularly in low-resource settings, will never receive a definitive diagnosis of their condition.
- Children and young people with genetic disorders are living longer thus posing a challenge as they transition into adult palliative care services.

StarPALS (Paediatric Advance Life Support) is a dedicated children's palliative care service that supports children living with life limiting conditions and their families in Singapore. Funded by a government grant for four years, Star PALS aims to improve the lives of families who struggle with one of life's most difficult challenges using a novel approach. Different components of its comprehensive service elements are customised to meet often myriad and unique needs.

When the child has a genetic condition (like 7 year old Vera who has Trisomy 18, pictured below with her mom) the disease trajectory can be unpredictable. However, parallel planning ensures that one is always prepared for the worse, while living life to the fullest in the present. In these situations, provision for respite becomes very important. The often single caregiver is able to access breaks when we send in Medi Minders. These are trained volunteers who help look after the child for a few hours such that the tired caregiver can rest, even for a moment. Vera enjoys sessions with our music therapist who helps connect the whole family together with songs. Melodies would be created by everyone at home, who are encouraged to grab an instrument each like players in a symphony! This way, our young patient not only gets her own special time, the whole family is drawn even closer together, sealing memories of joyful merrymaking.

StarPALS hope to continue improving the quality of life of all our clients like Vera but would need to be able to demonstrate meaningful yet robust outcomes that make sense to funders and more importantly, policy makers, so that children like Vera no longer have to live in the shadows but emerge stronger and happier.

starpals
COLLABORATIVE CARE FOR CHILDREN

Palliative care for children with malnutrition in Malawi

"Many of the children we see with malnutrition have complex social backgrounds and are poor. For children with recurrent malnutrition, it is often due to neurological damage, which affects their ability to feed, thus putting them at risk of developing severe malnutrition. Therefore palliative care should help the child and family to prevent malnutrition where possible or facilitate support when it occurs."

Cornelius Huwa
Umodzi

Umodzi children's palliative care is based at Queen Elizabeth Central Hospital in Malawi. It started in 2002 and endeavours to improve the quality of life of children and their families needing palliative care. The clinic recognises the need to work with care givers and the wider community thus a home based care programme has been the supporting backbone to the community related efforts by Umodzi clinic.

With the presence of three dedicated nurses, one clinical officer, one doctor and two play therapists, Umodzi has been able to provide skilled counselling, symptom control, empowerment of family members, organisation of discharge and linkage with home based care. Patients seen at Umodzi come from all over Malawi and home visits are carried out in the southern region. The programme reaches about 500 patients per year and sees about 30-40 new patients per month. 5% of Umodzi's patients have malnutrition of various degrees. Many of the children that are seen with malnutrition are those with cerebral palsy and other neurological challenges, and those with severe HIV disease. These children present with complex symptoms and social problems.

Providing palliative care to malnourished children is at the core of Umodzi's business. Umodzi helps the caregivers to understand the illness and symptom management, empowers them to care for the child and links them to social support systems in the community. Umodzi continues to champion children's palliative care and spearheads mentorship and transfer of skills to other providers from district hospitals from all over Malawi.

- 14.12% of children in need of palliative care at the end of life have protein energy malnutrition.[8]
- The Millenium Development Goals had the reduction by 50% of malnutrition in children under 5 years between 1990 and 2015.[26]
- India and parts of Africa have the highest prevalence of malnutrition.[27]
- Malnutrition is the underlying contributing factor in about 45% of all child deaths, making children more vulnerable to disease.[28]

UMODZI

TITHANDIZANE U MODZI

Palliative care for children with rare diseases in Australia

"Particular attention must be paid to the need for palliative care ….. bearing in mind the considerable diversity of the problems involved ….. the great variety and fragmentation of the diseases in question, which are often rare and demand highly-specialised measures. Given the above considerations, it is indispensable to organise dedicated palliative care networks for this age group that can guarantee the quality and specialisation of the action needed together with a global and multi-dimensional care for the children and their families."

Benini et al 2008[32]

- There are approx 7,000 different rare diseases and disorders with more being discovered daily [29].
- An estimated 350 million people worldwide suffer from rare diseases [29].
- Approximately 50% of people affected by rare diseases are children [29].
- Rare diseases are responsible for 35% of deaths in the first year of life[29].
- Of the nearly 7,000 rare diseases identified, only 5% have any treatment option [30].
- While individual rare diseases have small populations, collectively they account for more than the AIDS and cancer communities combined [31].

The Victorian Paediatric Palliative Care Program (VPPCP) is an alliance between two tertiary paediatric centres (The Royal Children's Hospital (RCH) and Monash Health), and Very Special Kids (VSK), an organisation which runs a children's hospice and family support programme. The VPPCP is a state-wide service operating using a consultation-liaison model since November 2000. The multidisciplinary team comprised of health professionals from medical, nursing, social work and occupational therapy backgrounds, assists in the care of around 180 children with life-limiting conditions across the home, hospital and hospice settings each year.

Significant challenges have been faced in providing specialist care to a relatively small and diagnostically diverse patient population spread across a large geographic area. The VPPCP has developed close working relationships with other organisations and teams including the Developmental Medicine team at the RCH and the clinical ethics service at the Royal Children's Hospital. They work closely together to ensure children with life-limiting forms of illnesses, including rare diseases, are recognised early and receive support around symptom management, physical care, respite and psychosocial issues. A key area of concern is working with families to make the best possible treatment decisions for the child and to ensure they are cared for in a place where they feel safe and supported. One of the challenges is the prognostic uncertainty commonly encountered in children with rare diseases but the palliative care team is able to move in and out of the family's life over months and even years according to what is needed. VPPCP hopes to contribute more in the future to research in order to develop a greater capacity to care for children and their families.

The Royal Children's Hospital Melbourne

Ruby and her family © Photo by Gavin Blue, Heartfelt

Palliative care for bereaved children in Zimbabwe

"The pain and suffering that children who are bereaved go through is immense, and it is important that we provide bereavement services that will support them and enable them to work through their grief."

Val Maasdorp
Island Hospice and Healthcare

Island Hospice and Health Care (Island) was conceived in response to a need in the community for palliative and bereavement care services, and has provided a comprehensive bereavement counselling service for all ages since its inception in 1979. Besides providing ongoing support for families whose relatives died in hospice care, the bereavement service has offered individual, couples and family therapeutic sessions, a wide range of bereavement support groups for widows, family survivors of suicide and other traumatic deaths, adolescent support groups and an extensive programme of children's groups.

Bereaved children's groups were developed in 1992, offering a day long programme of activities, support and sharing for bereaved children from the ages of 5-20 years in tandem with family counselling and ongoing support. Minor adjustments, including regularity of group sessions affected by diminished human resources, have been integrated in response to changes and demands created by political and economic instability in the country, but the programme in essence remains valid and appropriate as bereavement support for children. The Young carers group also supports those bereaved children who have also, by force of circumstances, found themselves caring for a dying relative.

Partnerships have been developed since 1998 between Island and various orphan care systems, including established children's homes and community groups where a high orphan population exists. A programme that integrates a direct service for children, training for community volunteers working with children and support for the carers has been successful. Professional support and supervision for primary and secondary carers is an integral part of this programme, acknowledging the stress of caring for often terminally ill children whilst they themselves are HIV+ and bereaved.

- In the UK a parent of a child under 18 dies every 22 minutes, i.e. 111 children are bereaved of a parent every day [33].
- In the UK 1 in 29 schoolchildren has been bereaved of a parent or sibling [33].
- In low-resource settings, and where HIV is prevalent the numbers of bereaved children is high e.g. in Zimbabwe approximately 1.1 million children are orphans [34]. In Uganda approx 14% of children <18 years are orphans with 20% of children 6-17 years being orphans [35] .
- There are approx 40 million child orphans in the world, many of whom would benefit from bereavement support [34].

Island Hospice & Healthcare
CARE / COMPASSION / IMPACT

PART TWO:
Other hidden groups

Palliative care for young adults in England

"Young adult hospices are about living, laughter, fun and generally being young adults. My team from The J's pulls together my care, quality of life is the utmost importance as you want to be able to live the life you have left!"

A Patient
The J's Hospice

The J's Hospice provides specialist palliative care for young adults with life-limiting and life-threatening conditions, giving high quality care and promoting independence through empowerment. The care is available to all young adults aged 16-40 who are registered with an Essex GP and is provided in their own homes. At the J's Hospice we work in partnership with multi-disciplinary teams and collaboratively with in-patient hospices and other palliative care providers to achieve a seamless service for our patients and their families

The service was established in October 2009 and has since cared for 152 patients and families. They are currently caring for 85 patients and their families and approximately 20 bereaved families. At 18 years old, patients with life-limiting and life-threatening illnesses leave children's services and this can be a worrying time for families. Due to improved medicine and science, patients are living longer than expected. The J's aim to provide specialist advice, support and advocacy, helping young people to find their way when transitioning from children's services. Practical nursing care, symptom control and pain management along with end of life care at home are key components of care, as is bereavement support. The J's runs groups for young people and addresses their physical, social, psychological and spiritual needs.

At The J's they aim to empower young adults so their voices are heard, support them in terms of independence and life choices, and improve their quality of life, as well as putting things in place for the end-of-life and supporting them and their families in their end-of-life care choices.

- The transition from children's to adult services can be a difficult one for young adults complicated by deteriorating health alongside normal developmental changes [36].
- In the past 10 years in the UK, there has been an increase in prevalence in 16-19 year olds by 44.8% due to increased survival rates and highlights the need for palliative care services for young adults [37].
- Definitions of adolescents and Young Adults vary, with age ranges varying between 15 and 40 years of age, with the most common being between 15 and 29 years of age [38].

THE J's HOSPICE

Palliative care for people with psychiatric illnesses in India

"Mental illness still remains the most stigmatised and neglected area in health care. Families are shattered and isolated. There is a person centred philosophy both in mental health and palliative care; which is compassion and aiming at little but important things that mean a lot to everyone. Palliative care should be inclusive to all; and there should be a change from a single minded focus on cure to a more adaptive approach in mental health care."

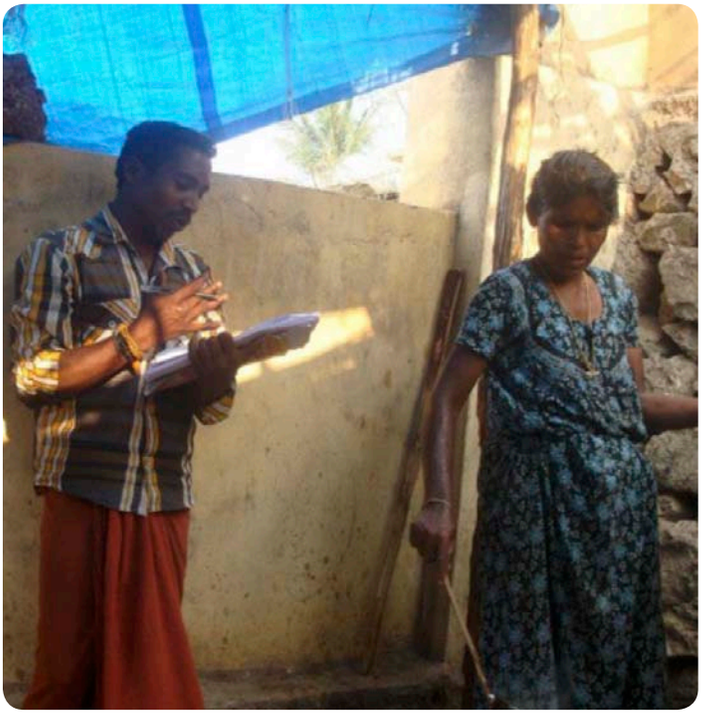
Chitra Venkateswaran
Mehac

Mental disorders cause considerable burden on individuals, families and societies causing a great deal of suffering. Human, social and financial resources are needed to provide access to effective and humane treatment for people with mental disorders. This burden reaches an enormous magnitude in a country like India. The palliative care movement in Kerala, influenced the initiation of Mehac Foundation which is based on the philosophy that the shared values of palliative care and mental health care contributes to the well being of an individual, family and thus the society.

Mehac Foundation (based in Kerala) delivers services rooted in the community aiming to improve the quality of lives of people suffering from mental illnesses and their families. It incorporates the palliative care principles to provide compassionate care specific to mental health with community participation. The model promotes a public health approach and focuses on well-being and stability and not only on symptom control. Mehac prioritises the poorest and the most vulnerable by planning long-term care with regular home care visits and taking care of other physical illnesses that develop during the course.

Mehac works by establishing local partnerships with Panchayats (Local Governing Bodies at the village level), other NGOS, Health Services, Medical Colleges and long term care homes. The local partners own the programme with an active role in planning and implementation of the service. Since it started in 2008, Mehac provided care to nearly 2000 patients and their families. Currently having units in four districts in Kerala, Mehac has been able to create a space for mental health at the grass roots level, demonstrate examples of public-private-NGO partnerships, take a proactive role in advocacy and awareness issues and enable preventive care, treatment and rehabilitation.

- By the year 2020 it is estimated that psychiatric and neurologic disorders will account for 15% of the total burden of all diseases [(39)].
- As many as half the people with a severe mental illness (e.g. schizophrenia), live in the community without treatment [(40)].
- People with severe mental illness have a reduced life expectancy that translates to a 13-30 year shortened life expectancy [(41)].
- People with pre-existing mental health problems who develop a life-limiting illness are possibly among the most underrepresented and deprived populations in our society [(42)].



MENTAL HEALTH ACTION
Strengthening Mental Health Care....

Palliative care for people with HIV in Uganda

"Patients suffering from HIV/AIDS have physical needs for comprehensive symptom management, as well as psychosocial, family, spiritual and end-of-life care –this therefore requires integration of disease-specific and palliative care services…. Palliative Care is an essential component of the care of people with HIV …and needs to be integrated into all services."

Jane Nakawesi
Mildmay Uganda

Mildmay Uganda is a local non-government not-for-profit organisation set up 16 years ago to transform HIV care. They set out to demonstrate best practices in both paediatric and adult HIV and AIDS care and treatment and to train health and non-health workers in Uganda (and other African countries) in such care. Mildmay supports sixteen (16) districts in the central region of Uganda in comprehensive HIV services delivery as part of an integrated District Health System. To-date Mildmay Uganda supports more than 84,772 people living with HIV, 6,585(8%) of these are children. 81% are on ART.

The outpatient clinic at Mildmay provides comprehensive HIV prevention, care and treatment services for children, adolescents and adults including provider initiated Counselling and Testing, HIV care and treatment including antiretroviral therapy, Sexual and Reproductive Jealth, TB screening, treatment and prevention services, nutritional rehabilitation, counselling, pastoral and social worker services among others. Mildmay Uganda runs an inpatient unit for both children and adults who present with severe opportunistic infections such as severe pneumonia, tuberculosis, cryptococcal meningitis among others. Kisakye youth centre is an adolescent and youth health service. Youth related health programmes including adolescent sexual reproductive health, transition clinic, life skills, behavioural change programmes, counselling and career guidance among others are offered.

An important aspect of Mildmay's work is to train and empower others to care for people with HIV, with their mission being to model quality and sustainable prevention, care and treatment for HIV and other priority health issues, using a family-centred approach, together with training, education and research.

- There were 35 million people living with HIV around the world in 2013, with 2.1 million new infections that year and 1.5 million deaths [43].
- Of the 35 million people living with HIV in the world, 19 million do not know their HIV status [43].
- Adolescent girls and young women account for 1 in 4 new infections in sub Saharan Africa [43].
- There were 12.9 million people receiving antiretroviral therapy globally at the end of 2013 – 63% of people with HIV were not receiving ART [43].
- Fifteen countries account for nearly 75% of all people with HIV, the majority of whom are in sub Saharan Africa [43].

MILDMAY
UGANDA

Palliative care for prisoners in South Africa

"Knocking at the prisons' doors has improved access to palliative care - the 'Hidden Lives, Hidden Patients' in prisons are now accessing palliative care."

Zodwa Sithole
HPCA

In KwaZulu Natal (KZN), the Hospice and Palliative Care Association of South Africa (HPCA) set up a pilot programme to address the palliative care needs of prisoners. A formal partnership was established in 2009 with the KZN Department of Correctional Services (DCS) with the focus to equip health staff within the DCS to provide palliative care to inmates. Staff within the prisons (e.g. chaplains, social workers, psychologists, nurses etc.) have been trained in palliative care and at Westville Correctional Centre all the staff have been trained in using the APCA African POS.

Regular palliative care ward rounds take place with a palliative care trained prison doctor, with input from the hospice team as appropriate. In some centres prisoners have been trained to support other inmates and are sleeping in the hospital wards or palliative care units to assist other inmates as needed. Access to essential medicines for palliative care has been made possible through the correctional centre pharmacies and resources such as guidelines, books etc. made available to staff. Discharged patients are being referred to their local hospice or palliative care service as appropriate.

More prison staff need training on palliative care, and there are challenges in caring or individuals within the system e.g. those awaiting trial cannot be admitted to the palliative care ward as this is for sentenced prisoners only. Palliative care is not a priority in the prisons and so trainings etc. may be cancelled at short notice due to competing demands. However, despite this, the programme has made a big impact on the quality of life of offenders with life threatening illnesses.

- More than 30 million men and women in the world are held in prisons and other closed settings, of whom one third are pre-trial detainees[44].
- In October 2013, South Africa had a prison population of 156,370 and 294 prisoners per 100,000 of the national population [45].
- All prisoners have the right to receive health care, equivalent to that available in the community [46].
- HIV prevalence among prisoners is up to fifty times higher than that of the general adult population, and particularly high amongst women [44].
- The combination of TB and HIV is responsible for a high mortality rate in African prisons [47].

HPCA care & support
Hospice Palliative Care Association of South Africa

Palliative care for sexual minorities in Zimbabwe

"Access to palliative care for marginalised populations in general, and in Africa in particular is extremely tenuous – it is hoped that this study will raise awareness of the right to palliative care for sexual minority groups."

Jennifer Hunt
Zimbabwe

Currently, and particularly in Africa, little is known about the palliative care needs of these groups. Therefore an appraisal to identify palliative care needs of sexual minorities in Zimbabwe was undertaken on behalf of the Open Society Foundations (OSF) in collaboration with the Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) with guidance and collaboration from the principal investigator of a similar project being undertaken in the United Kingdom (ACCESSCare) [48]. 75 participants from 4 sites across Zimbabwe, were interviewed on issues related to life-limiting conditions specific to the targeted populations, access to care, and care needs of key populations. Participants represented urban centres, border communities and tribal/ethnic populations.

Little attention in relation to palliative care, has been given to sexual minorities and sex workers whose sexual behaviours promote higher incidence of some life-limiting illness due to risk behaviours which may be linked to discrimination[49]. Holistic care for African lesbian, gay, bisexual and transgender (LBGT) persons, sex workers and men who have sex with men (MSM) should be designed to give equitable access to quality palliative care, without marginalisation or disregard for special care needs in different care settings. It is highly likely that due to their marginalised and sometimes stigmatised status, these groups are not able to access mainstream care. Palliative care providers and health workers are likely to benefit from this study by raising their awareness of the human right to health care of marginalised populations along with the palliative care needs of this group.

- The United Nations Development Programme have prioritised strategies to secure the human right to health care for these populations [50].
- Socially excluded populations, such as sexual minorities, are known to receive lesser access to end of life care [51].
- Lesbians have a high prevalence of breast, cervical and ovarian cancer [52].
- Gay men have a higher overall prevalence of cancer compared to heterosexual men and are at greater risk of developing anal cancer and HIV related cancers [53].

OPEN SOCIETY FOUNDATIONS

Hospice And Palliative Care Association of Zimbabwe (HOSPAZ)

Photo: Sexual Rights Centre, Zimbabwe

Palliative care for those affected by war, persecution or natural disasters

"The provision of palliative care in times and places of conflict is fraught with personal and infrastructural difficulty. In meeting theses challenges, healthcare providers have the potential to be positive agents of change. The challenges are great, but the potential rewards even greater." [57]

Nathan Cherny
Israel

There are many situations that lead to individuals being displaced, living in refugee camps and at the mercy of aid and other agencies. Such individuals experience a variety of challenges to accessing and sustaining palliative care. Links are needed between refugee/internally displaced camps, clinics, hospitals and palliative care services, however challenges for providing such care include access to pain control, communication, communicable diseases, the unpredictable nature of the care setting, large numbers of children/ orphans, a breakdown in community systems and networks, and co-ordination of care[54]. In 2000 the WHO/UNAIDS[55] described palliative care as an essential activity, thus ways of providing such care need to be developed within refugee and disaster situations.

There is commitment within the palliative care community to ensure access to palliative care to all those affected by war, persecution or natural disaster, and work is underway, coordinated by the International Association of Hospice and Palliative Care (IAHPC), ICPCN and WHPCA to co-ordinate work in this area, working with international organisations such as the World Health Organization (WHO), Medicins Sans Frontieres (MSF), Save the Children, UNICEF, UNHCR and others such as the International Medical Corps. A task group has been set up to explore the palliative care response to such situations, linking in with the recent WHA[3] resolution on palliative care that emphasises the right to palliative care for all.

- At the end of 2013 there were 51.2 million people forcibly displaced worldwide including refugees, internally displaced people and asylum-seekers [56].
- Life- threatening illness is endemic and often occurs in places of conflict. In these circumstances care is often compromised or complicated [57].
- The Geneva convention recognises the special status of the wounded or sick, and emphasises the separation of medical care from military conflict [58].
- The recent earthquake in Nepal has left 450,000 people displaced, with entire villages flattened across the country [59].

Burmese Refugees © 2012 Didini Tochhawng, Courtesy of Photoshare

Palliative care for people with dementia in Wales

"It is crucial that health-care providers work together with individuals living with dementia and those who support them to provide the medical, emotional and spiritual support needed. A person-centred approach to palliative and end-of-life care combines good physical care with compassionate communication and support to minimise the person's emotional and spiritual distress, while maximising their overall comfort and well-being."

Mary E Schulz
Alzheimer Society of Canada

- Dementia is characterised by a progressive decline in multiple areas of function, including memory, reasoning, communication and the ability to carry out daily activities [60].
- In 2013 there were an estimated 44.4 million people with dementia worldwide and 62% of these live in developing countries [61].
- The prevalence of dementia increases with age, and the median length of survival from diagnosis to death is 8 years [62].
- Dementia is associated with complex needs and people with dementia (and their carers) have been shown to have palliative care needs equal to those of cancer patients [60].

There are many challenges to supporting patients and their families through the course of their dementia e.g. referral to palliative care services come late in the course of the illness; many die in hospital, despite not wanting to; pain and other symptoms are under recognised and treated; and, there is little recognition of spiritual and psychological needs.

Recognising these challenges, a new and innovative project was started in 2014 to integrate the knowledge and skills of two specialist services within Blaenau Gwent, South Wales, UK - Hospice of the Valleys (a provider of Specialist Palliative Care) and the Alzheimer's Society. The aim of the project was to work in partnership to improve and develop effective palliative care for people with dementia and their families by working with existing health and social care professionals in order to overcome the challenges, and provide education for health professionals on the need for palliative care for people with dementia.

Between January 2014 and January 2015, 63 patients and their families were supported by the Challenge Project, 54% in residential and nursing care, 43% in their own home and 3% in an inpatient specialist mental health setting. Of patients who have died during that period less than 10% ended up dying in hospital with the remainder dying in their existing place of care. The project is also being used as the basis of a research study evaluation supported by the Marie Curie Palliative Care Research Centre, Cardiff (MCPCRC). The Board of Trustees of Hospice of the Valleys has now extended this pilot project and the research evaluation will help guide its development in the future.

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Conclusion

Whilst palliative care services have developed, there are still substantial gaps in the system and many people with life-limiting illness who, tragically, fall through those gaps. There has been much development in palliative care throughout the world, however there is still a long way to go. In many countries, there are no or limited services which people can access, and even in those countries where palliative care is well developed, there are those who, for a variety of reasons, are unable to access them.

This year as we celebrate World Hospice and Palliative Care Day, and remember those hidden patients with hidden lives, we echo the statement made at the WHA in May 2014, in response to the resolution on palliative care [3]. The statement, made on behalf of the Worldwide Hospice Palliative Care Alliance (WPCA), the International Association for Hospice & Palliative Care (IAHPC), the International Children's Palliative Care Network (ICPCN), and palliative care associations worldwide, urged member states to 'implement the recommendations in the resolution' and 'tear down barriers to palliative care and put an end to unnecessary suffering' [63]. Never before has there been such global recognition of the need for palliative care and a commitment to providing it [64]. Thus as the palliative care community we need to support governments and other organisations to increase access to palliative care services for all in need so that we can reduce the number of hidden patients with hidden lives.

The Worldwide Hospice Palliative Care Alliance initiated World Hospice and Palliative Care Day to become the campaign tool for palliative care in countries across the globe. The intention is to have a combined voice advocating for universal access to affordable, appropriate, quality palliative care. We continue to lobby governments and health care providers to raise awareness of the benefits of and need for palliative care. It is also important to engage communities in discussion about palliative care so that people needing this care know the benefits and where to find palliative care services.

The Global Atlas estimates that worldwide over 20 million people would benefit from palliative care. However, less than 10% of the need for palliative care is currently being met. This year's campaign "Hidden Lives, Hidden Patients" highlights groups that have additional barriers to accessing palliative care. These groups include children; the elderly, in particular people with dementia; the LGBTI community, people living with disabilities, people with psychiatric disorders, people living in distant or rural communities, people in prisons.

We encourage you to use the World Day materials to improve awareness of the need for palliative care and as you do so, consider the 'hidden patients' how can you reach out to them and help them access the care they need.

Dr Liz Gwyther
WHPCA

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About the Worldwide Hospice Palliative Care Alliance

The Worldwide Hospice Palliative Care Alliance (WHPCA) is a global action network focusing exclusively on hospice and palliative care development worldwide. Its members are national and regional hospice and palliative care organisations and affiliate organisations supporting hospice and palliative care.

Our vision is a world with universal access to hospice and palliative care.

Our mission is to foster, promote and influence the delivery of affordable, quality palliative care.

We operate through work groups based in different national hospice and palliative care organisations around the world.

Worldwide Hospice Palliative Care Alliance

34-44 Britannia Street

London

WC1X 9JG

Tel: +44(0)207 520 8200

Fax: +44(0)207 278 1021

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The International Children's Palliative Care Network (ICPCN) is a global action network focusing exclusively on palliative care for children worldwide. Its members are individuals and organisations working in and supporting the development of children's palliative care.

Our vision is to live in a world where children's palliative care is acknowledged and respected as a unique service, and every child and young person with life-limiting or life-threatening conditions and their families can receive the best quality of life and care regardless of which country they live in. Also that the total need of life-threatened or life-limited children should be met to encompass physical, emotional, spiritual and developmental aspects of care.

Our mission is to achieve the best quality of life and care for children and young people with life-limiting conditions, their families and carers worldwide, by raising awareness of children's palliative care, lobbying for the global development of children's palliative care services, and sharing expertise, skills and knowledge.

We operate in five key areas:

Communication, Advocacy, Research, Education and Support & Development

International Children's Palliative Care Network

Cluster Box 3050, Assagay, 3624, South Africa

Tel: +27(0)828 974 420

Email: admin@icpcn.org

www.icpcn.org

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