2020
INTERNATIONAL YEAR
OF THE NURSE AND
THE MIDWIFE

PALLIATIVE CARE
Celebrating Nurses Contributions



icpcn
international children's
palliative care network

whpca
worldwide hospice
palliative care alliance

INTERNATIONAL ASSOCIATION
FOR HOSPICE & PALLIATIVE CARE

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Library of Congress Cataloguing-in-Publication Data

ISBN: 978-1-8384327-0-6

To cite this document, please use this format:

Downing J (Ed) (2021) Palliative Care: Celebrating Nurses Contributions. Report by ICPCN, WHPCA, IAHPC. Bristol: ICPCN.

ISBN: 978-1-8384327-0-6

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PREFACE

LORD NIGEL CRISP
CO-CHAIR, NURSING NOW
Chief Executive of the NHS in England and Permanent Secretary of the UK Department of Health 2000 to 2006.

This report is a wonderful celebration of the work that nurses do in palliative care in countries around the world. It is also provides a very clear demonstration of what more could be achieved given greater priority and more investment

The stories described here come from more than 20 countries and cover every aspect of palliative care from service development and education to research and leadership with service delivery at their heart. The case studies range from nurses working alone in the most remote and resource-poor areas to others operating at the national level, all seeking to influence policy and provide leadership within both their profession and their discipline.

What links them is the passion, compassion and perseverance of all the nurses involved. These are, of course, the very qualities needed to develop further what is still a very young discipline, albeit one based on the experiences of generations of nurses in caring for the sick and the dying.

There are many reasons to be fearful about the future at the moment. Climate change, conflict within and between countries, and the continuing poverty of millions make the outlook gloomy. And COVID-19 has demonstrated just how vulnerable our joined-up global world is.

The stories in this report are rooted in science, knowledge and human kindness and can offer us all hope for the future. Palliative care has come a very long way in the last 50 years and is now recognised as an important part of any health and care system, although not yet properly resourced. The 2017 Lancet Commission on Palliative Care and Pain relief set out the basic package of care needed and introduced the simple idea of measuring our health systems by their ability to relieve suffering.

Nurses with their holistic view of health, which embraces the physical, mental and social aspects of health, have always been at the heart of palliative care but they have not always been permitted or able to work to their full potential in doing so.

We created the Nursing Now campaign to improve health globally by raising the profile and status of nursing. Palliative care is an area where nurses are taking on advanced practice and extended roles in many countries, being innovative and intuitive in developing services and working with patients and relatives. They are largely modelling the future that we are seeking.

I believe that we are seeing new trends in both palliative care and nursing. The public are wanting more personal and holistic care that takes account of all our needs – physical, mental, social and spiritual – and palliative care is the very model of this. At the same time the true value and potential of nursing is beginning to be better recognised in many countries - with nurses now playing leading roles in long term conditions, primary and community care, and, of course, in palliative care.

The pandemic may set some of this back as we struggle to recover, but it may also help accelerate these changes. The wide-ranging and very professional roles played by nurses during COVID-19 have been very visible and greatly admired by the public, and the importance of relieving suffering and providing good quality care for the dying have become so much more evident.

I am sure we will see further and, I hope, more rapid development in the future. In the meantime it is a pleasure to read these stories and celebrate the achievements of nurses everywhere who are working in palliative care.

INTRODUCTION

We are delighted to be able to bring you this report celebrating nurses' contribution to palliative care provision around the world.

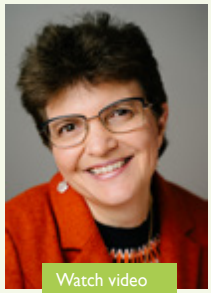
The first ever State of the Worlds Nursing Report was published in 2020 by the World Health Organisation (WHO), the International Council of Nurses (ICN) and Nursing Now. It recognises the unique role of the nurse in the provision of Universal Health Coverage (UHC) and demonstrates a commitment to ongoing progress in nursing development throughout the world, and the need to invest in nursing education, create new jobs, and strengthen nurse leadership. Nurses play a vital role throughout the health system and there is much to celebrate in nursing, whilst recognising the inequities around the world and all that still needs to be done to strengthen nursing globally. The Nursing Now campaign, launched in 2018, ran until the end of 2020. It focussed on: ensuring that nurses and midwives have a more prominent voice in health policy-making; encouraging greater investment in nursing; advocating for more nurses in leadership positions; encouraging research and sharing examples of best nursing practice. The campaign's aim was about raising the status and profiles of nursing. Thus, in 2020, the International Year of the Nurse and Midwife, we felt it was fitting to compile this report to celebrate the work of nurses around the world, in palliative care.

The report was due to be published at the World Health Assembly in 2020, but like many other things, it was delayed due to the COVID-19 pandemic. However, whilst the release of the report was delayed, the focus remains the same – to Celebrate Palliative Nurses. The nurses in this report are all passionate about driving forward the palliative care agenda using ingenuity and innovative thinking. The report shines a spotlight on many individuals, but highlights the importance of teamwork and celebrates what nurses can do.

In my work with the International Children's Palliative Care Network (ICPCN), previously with the African Palliative Care Association (APCA) and international palliative care development, I have been privileged to meet many nurses working in palliative care around the world. Some are nearing the end of their careers, are looking at what they have learnt and can pass on to others, are acting as role models and providing inspiration to young nurses. Others are just beginning their careers, are eager and keen, want to learn, and have the strength and ability to push forward, overcoming barriers and pioneering palliative care in their own settings. I have been fortunate to hear of their stories, to provide a guiding and mentoring arm, and hopefully in some way to inspire them, to step out of their comfort zone, and to see what they as nurses can achieve.

I always wanted to be a nurse as I was growing up, and I am proud to be a nurse, and to have played a small part in the development of palliative care for children and adults. As I read the stories of the nurses featured in this report, I am humbled by all that they have done, and are continuing to do, in often challenging and difficult situations. So please join us in celebrating nurses contribution to palliative care.

Prof Julia Downing
Chief Executive, ICPCN.



Prof Julia Downing

"I always wanted to be a nurse as I was growing up, and I am proud to be a nurse, and to have played a small part in the development of palliative care for children and adults"

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WHY CELEBRATE PALLIATIVE NURSING?

2020 was designated by the WHO as the International Year of the Nurse and Midwife[1]. A year to reflect on the skills, the commitment and the expert clinical care they bring, and the impact they make on the lives of so many[2].

Whilst 2020 was not the year most of us anticipated due to COVID-19, it was however a year when we saw the work of nurses and midwives being pivotal to the multi-disciplinary team.

Throughout the world, nurses have been taking their place in the fight against COVID-19. Nursing has been at the forefront of care provision, giving nurses the opportunity to demonstrate the knowledge, skills and commitment required to provide high quality evidence-based care[3]. At such a time, we want to take this opportunity to recognise and value the work of nurses around the world in palliative care.

With an estimated 27.9 million nurses globally[4], nurses make up the largest group of professionals working in the health care sector, accounting for approximately 59% of health professionals globally. However, the State of the World's Nursing Report estimates that 80% of the world's nurses are found in countries that account for half of the world's population, and that in 2018 there was a global shortage of 5.9 million nurses, with 89% of these concentrated in low and middle-income countries (LMICs)[4]. At the same time, it is recognised that nearly 90% of the nursing workforce are female, leading to gender-based issues being prevalent in nursing, such as pay gaps, inequality, discrimination in promotion, leadership and decision-making positions, and with COVID-19 they often fear for their safety providing care without adequate PPE, thus putting themselves and their families at risk. Due to many of these issues, the role and value of nursing has not always been appreciated or valued.

2020 also saw the 200th anniversary of the birth of Florence Nightingale. Within palliative care we remember that Dame Cicely Saunders, often seen as the founder of palliative care, trained both as a nurse and a social worker before going on to train as a doctor. It was a photo of her as a nurse that was used in the service booklet for the celebration of her life in Westminster Abbey. We remember both of these women as pioneers in their fields, in the fields of nursing and palliative care, and they set the scene for the work that we do as palliative nurses today.

With the recognition and value of nurses as a profession varying from country to country, it is important that we shine a spotlight on the contribution that nurses are making globally in palliative care. Whether this is as a pioneer working on their own, trying to promote and

CONTINUE

59%

OF HEALTH PROFESSIONALS GLOBALLY ARE NURSES



1 https://www.2020yearofthenurse.org
2 https://www.england.nhs.uk/year-of-the-nurse-and-midwife-2020
3 Downing et al. 2020. Palliative Care in the COVID-19 Pandemic Briefing Note: "Leaving No One Behind": Valuing & Strengthening Palliative Nursing in the time of COVID-19. http://globalpalliativecare.org/COVID-19/uploads/briefing-notes/briefing-note-leaving-no-one-behind-valuing-and-strengthening-palliative-nursing-in-the-COVID-19-era.pdf
4 WHO, ICN, Nursing Now. 2020. State of the World's Nursing. Geneva 2020. https://www.who.int/publications/i/item/9789240003279

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develop palliative care services, or as a leader in a country where palliative nursing is recognised for the unique role that it plays, but is still seen as a relatively new profession, with the ongoing need to develop and utilise its own evidence base.

The World Health Assembly resolution WHA67.19 recognised the importance of developing palliative care services around the world in order to minimise the avoidable suffering for millions of patients and their families. It also recognised the importance of palliative care training at different levels, and the need for both generalist and specialist palliative care services. Thus, recognising that all nurses will need to provide some level of palliative care services provision with a smaller number needing specialist skills. Importantly, palliative care provision is a core component to achieving UHC[5] and the Sustainable Development Goals (SDGs)[6] with nurses playing a key role in implementation, both within generalist and specialist care. No global health agenda, such as palliative care, can be realised without maximising the contributions of nurses. Palliative nurses are needed not only for the provision of clinical care, but also for education, research, advocacy, service development and leadership within the field.

Nurses are vital to the provision of palliative care and have a pivotal, dynamic and progressive role in the development of palliative care globally. They have a broad range of skills and are in a unique position not only to shape palliative care, but the role of nurses within palliative care. The principles of nursing support the holistic philosophy of palliative care[7] with nurses trained to see value in life, and to see the individual as a whole person[8]. It is the nurse who will provide much of the care and support to patients and their families throughout the disease trajectory, and across the continuum of care, and are more likely to be present at the time of death than any other health professional[9]. The essence of palliative nursing lies within the nurse's relationship with the patient and the family. Palliative nursing reflects the whole-person philosophy of care across the life-span, seeing the patient and their family as the centre of the care being provided. The goal is to promote quality of life, and relieve suffering, including at the end-of-life and into bereavement. The individual nurse is part of the health relationship – the nurse's relationship with the patient and family is crucial and it is this relationship, alongside knowledge and skills, that is central to palliative nursing. Coyle writes that the essence of palliative nursing is "to facilitate the caring process through a combination of science, presence, openness, compassion, mindful attention to detail and teamwork."[10]

Alongside providing excellence in clinical care, nurses have a broad role within the development and provision of palliative care. These include: the integration of palliative care into all levels of service delivery; the development of teamwork often with nurses leading the teams; assessment skills; communication and counselling, treatment and prescribing as appropriate; training and supervision, health promotion, leadership and

CONTINUE

"The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities, contributing to health or its recovery (or to a peaceful death) that he would perform unaided, if he had the necessary strength, will or knowledge."

(Henderson 1958)

80%

OF THE WORLD'S NURSES ARE FOUND IN COUNTRIES THAT ACCOUNT FOR HALF OF THE WORLD'S POPULATION

5 Universal Health Coverage - https://www.who.int/healthsystems/universal_health_coverage/en/

6 Sustainable Development Goals - https://sustainabledevelopment.un.org/content/documents/21252030%20Agenda%20for%20Sustainable%20Development%20web.pdf

7 Henderson V. 1958. Basic Principles of Nursing Care. London: International Council of Nurses

8 Downing et al Chapter 25: Role of the Nurse in Resource-Limited Settings. In Gwyther L, Merriman A, Mpanga Sebuyira L and Schietinger H. (Eds) A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa. 2006 Edition. APCA, Kampala, Uganda.

9 Coyle N (2015) Introduction to Palliative Nursing Care. In Ferrell BR, Coyle N, Paice JA. (Eds) Oxford Textbook of Palliative Nursing. 4th Edition. Oxford University Press. 3-10.

10 Coyle N (2015) Introduction to Palliative Nursing Care. In Ferrell BR, Coyle N, Paice JA. (Eds) Oxford Textbook of Palliative Nursing. 4th Edition. Oxford University Press. p6

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advocacy. Nurses must be able to advocate for their patients, but also for the provision of palliative care services, for education and training, and the availability of essential drugs.

Each and every one of you has played, and continues to play, an important part in the palliative care journey and we would like to celebrate all that you do. In 2020 we have seen palliative nurses honoured and recognised in different fora, for example the European Association of Palliative Care (EAPC) have highlighted nurses from around the world in their blog throughout the year[11], and St Christopher's Hospice set up its Pioneering Nurses programme[12] showcasing a network of pioneering nurses from around the world who are driving palliative nursing forward, are changing the face of palliative care and are at the cutting edge of their work. In this report we have celebrated the work of 27 nurses from around the world. Some of them you will have heard of, others not, but the key thing is that each one of them has a passion for palliative care, for the art and craft of palliative nursing, and is committed to making a difference in the lives of individuals, young and old, needing access to quality palliative care.

Choosing just 27 was hard: – who to include and who not to include; what were the criteria for inclusion; who recommended them; do we have people from a range of countries? However, as we celebrate the achievements of each of the nurses included here, we are celebrating the achievement of all nurses and midwives around the world seeking to provide palliative care and reduce unnecessary suffering. Our journey is not over yet. In many ways, this is still the beginning. We have come a long way, but there is still a way to go, and together we can continue the journey and continue to advocate for, lead, develop and implement palliative care services around the world.

5.9 MILLION

THE GLOBAL SHORTAGE OF NURSES IN 2018

MILLION + MILLION + MILLION
MILLION + MILLION + 900 000

89%

OF THESE CONCENTRATED IN LOW AND MIDDLE-INCOME COUNTRIES

"We have come a long way in the field of palliative nursing and end-of-life care but we still have a long way to go."

(Coyle 2015)

11 EAPC Blog

12 St Christopher's Pioneering Nurses Programme https://pioneeringnurse.stchristophers.org.uk

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"2020, the International Year of the Nurse and Midwife, has helped to shine a light on what nurses do and how they contribute to the societies they live in.

All nurses share important moments in the lives of their patients that shape the way they deal with their illnesses, and that has never been more important than in the midst of this pandemic.

Palliative care nurses provide that support at the most challenging of times while patients deal with diseases that cannot be cured, and with their own impending deaths. They help people to navigate their way through these troubled waters, and are often the most consistent health professional, the person who walks alongside them through the illness journey from diagnosis until the end of their life.

A palliative care nurse has to have the expertise and experience to advise on treatment options, side effects and pain management, but also to provide physical, emotional and psychological sustenance at the most difficult times in a person's life, and offer support to their families and loved ones.

On behalf of the International Council of Nurses, I welcome this important report, and salute all the world's palliative care nurses for their tireless work in helping people to live their entire lives to the full."

(Howard Catton, Chief Executive Officer, International Council of Nurses (ICN))

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Service Development

11 Sister Dona Samindra Ranasinghe – Sri Lanka

12 Patience Mbozi – Zambia

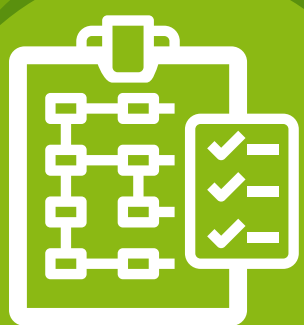
13 Jo Hockley – UK

14 Lynda Gould –China

16 Wan Ru Ng – Singapore

17 Ruth Wooldridge – UK

18 Clara Cullen – Argentina



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SISTER DONA SAMINDRA RANASINGHE
SRI LANKA

Samindra is a Nursing Officer working at the National Cancer Institute (NCI) Sri Lanka. She has been working in palliative care since 2014 and undertook her training in palliative care at Pallium India in Kerala. When she started working at the NCI in 2012 palliative care was not known in Sri Lanka. However, after she had received training she realised what a big difference she could make as a palliative care nurse. This was emphasised as she undertook a training-of-trainers course through Asia Pacific Hospice Palliative Care Network (APHN). She then focused on palliative care and organised several awareness programmes in her institute for all health professionals, and participated as a resource person for palliative care programmes from other hospitals and organisations. Initially they established a clinic in the hospital and following this they established a palliative care unit. At first Samindra was working in the palliative care clinic, but gradually the team has grown so that there are now four doctors, four permanent nurses, six volunteer nurses, one social worker and a medical orderly. With the help of donations, they have managed to equip the palliative care unit. Samindra is committed to providing quality palliative care services in her hospital and to increase understanding and recognition of palliative care in Sri Lanka.

"Nurses care for and support patients and families during one of life's most difficult journeys, helping patients to understand their conditions and educating their caregivers about management of problems and symptoms that may arise. They are a cornerstone of palliative care."
(Liliana De Lima MHA, Executive Director International Association of Hospice and Palliative Care (IAHPC))

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PATIENCE MBOZI SIMUUNZA
ZAMBIA



She believes that every student has the potential. Therefore, she believes that excellence can not only be expressed through knowledge but also in terms of skills and attitudes.

Patience is a Lecturer in the Nursing Department at Chreso University and was the Lead Palliative Care Nurse at the Cancer Diseases Hospital (CDH) in Zambia. She undertook the Diploma (HE) in Palliative Care at Nairobi Hospice with Oxford Brookes University, her BSc in Palliative Care at the Institute for Hospice and Palliative Care in Africa (IHPCA) in affiliation with Makerere University in Kampala, Uganda and her Masters of Palliative Care Nursing at Oxford Brookes University in the UK. She was identified as a key person for the ongoing development of palliative care in Zambia through the THET Integrate project run by the University of Edinburgh, the African Palliative Care Association and colleagues. The palliative care (PC) unit at CDH offers palliative care to all cancer patients and their families from diagnosis, using a multidisciplinary approach. The hospital is busy with the palliative care unit seeing up to 950 new patients per year. Many need palliative care as they have presented late for treatment. Since the unit's development and the recognition of the need for palliative care, the services provided by the unit in the hospital has increased, along with referrals.

Patience and her colleagues experience many challenges in providing palliative care, such as the need to increase the number of team members, as well as training more nurses within CDH, along with community volunteers so that they act as the link between the PC unit and patients in the community. Patience and the team are also keen to promote high-quality palliative care research within CDH to increase the evidence base for palliative care, and improve the quality of care. Patience continues to advocate for palliative care at every opportunity and is keen to raise awareness about the availability and appropriateness of palliative care services for all in Zambia. Alongside this Patience is an active member of the Zambia Oncology Nurses Society where she has served as their Vice-president since 2016 and represented them at international conferences and meetings.

Patience's educational philosophy is not only to produce a highly knowledgeable student but also a skilful student with good values, morals, and a good attitude. She believes that every student has the potential. Therefore, she believes that excellence can not only be expressed through knowledge but also in terms of skills and attitudes. She tries to foster an environment which enables a free flow of information between herself and the students and in which they feel free to express their fears and concerns.

With regards to her personal philosophy she aims to utilise the knowledge and skills attained through her education and clinical care practice to the maximum level, ensuring that organisational goals and interests are upheld in order for her to effect positively on her work and the quality of care provided for all in need.

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DR JO HOCKLEY
UNITEDKINGDOM



We need perseverance if we are going to be able to navigate the often-turbulent seas that innovation has to navigate.

Jo has worked in palliative care for over 30 years and had the privilege of working with Dame Cicely Saunders at St Christopher's Hospice. Her passion has been to disseminate palliative care knowledge within generalist settings. She set up two hospital-based palliative care teams (St Bartholomew's Hospital, London and Western General Hospital, Edinburgh) and following her PhD she has worked for the past 15 years in care homes undertaking various research and quality improvement initiatives. She currently works at the University of Edinburgh leading the work to establish a Teaching/ Research-active Care Homes (ToRCHs) Centre for excellence and community engagement to support training and quality improvement initiatives/research in care homes across South East Scotland. She has been recognised in many different forums for the groundbreaking work that she has been doing and was awarded an OBE for services to palliative nursing in 2013.

In 2008 Jo took up a job at St Christopher's. This time to set-up a Care Home Project Team (CHPT). Eventually, as a nurse consultant, she led a team of five palliative care clinical nurse specialists (CNSs). The first five years she was there were one of the most enjoyable periods of her career – the team was extremely effective and hard-working. Staff in care homes were caring for increasingly frail older people – they did not have cancer but had advanced, progressive, incurable diseases (dementia, heart failure, stroke etc) and so the focus was on palliative care and quality of life.

As part of the project, they implemented a palliative care framework called 'The Gold Standards Framework' (GSF Care Homes) and at the end of five years they had implemented the framework and set up a sustainability initiative across 71 Nursing Care Homes (NCHs). Prior to the implementation, they had collected information regarding advance care planning, do-not-attempt cardiopulmonary resuscitation, and the number of residents who managed to die in their place of choice. Before commencing the project only 56% of residents died in the NCHs and by 2013, 78% of residents had died in the 71 NCHs thus avoiding admission to hospital for the last week or so of life.

The vision for the ToRCHs Centre in Edinburgh is to have a centre that not only exemplifies excellence and community engagement for frail older people with multiple co-morbidities, but can also be the sustainability initiative that is lacking behind so many quality improvement initiatives. Jo hopes that such a vision can lead the way for excellence in the palliative care for frail older people living and dying with dementia and other co-morbidities in care homes.

Jo has learnt many things during her career. One thing is that she realised we must not impose a model of specialist palliative care, that has been modelled for people dying from advanced cancer in mid-life, onto frail older people dying at the end of their lives from multiple co-morbidities in care homes. She says that she was as guilty of that as anyone when she first went into NCHs 18 years ago. Staff in care homes taught her so much. Specialist palliative care must work hand-in-hand with geriatricians and care home staff to develop appropriate models of care for frail older people dying of very old age at the end-of-life. Another thing that she has learnt is perseverance. We need perseverance if we are going to be able to navigate the often-turbulent seas that innovation has to navigate.

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LYNDA GOULD
CHINA



After nearly 40 year's experience in the National health service ((NHS), in England as a nurse, manager and leader, Lyn, and her husband Alan, founded Butterfly Children's Hospices (BCH) and moved to China to pioneer children's palliative care services. Lyn has just retired as CEO and Chair of BCH and is Vice Chair of the International Children's Palliative Care Network (ICPCN), a speaker on children's palliative care at international conferences and events and is passionate about sharing her expertise in the development of children's palliative care services in low-and-middle-income countries (LMICs). In 2017 she was awarded an MBE (Member of the Most Excellent Order of the British Empire) for her services to the provision of palliative care to children in China.

From the start the goal of BCH was to develop palliative care services for children with families but in 2006 there was no understanding of children's palliative care and government priorities were to rebuild infrastructure such as roads, rail and businesses. So they decided to open a hospice facility to care for life limited abandoned children in the orphanage, in order to: demonstrate the concept and benefits of simple palliative care, work within the government system to get the concept and BCH introduced to government, develop a model which could be replicated across the system and establish BCH as a reputable organisation with high standards.

10 years on and China has developed significantly. There are fewer children abandoned and health and social carers are recognising the need for children's palliative care. The hospital system is improving and BCH is now established as a leader in children's palliative care in China and facilitating work with paediatric oncologists to educate and develop appropriate services, linking with community hospitals to provide end-of-life care for children and their families. BCH has supported the development of on-line support through social media, family support groups and one-to-one calls with families for advice and delivery of practical nursing in the homes. Education and research is integrated into each project, testing theory, learning and developing appropriate services. BCH has held 4 national conferences, provided speakers and held workshops at national conferences, published articles, given hundreds of interviews in the media and provided education through courses, media and one off events.

There have been many challenges along the way, including: a lack of understanding and suspicion of the concept of children's palliative care in society; a lack of statistics and research; lack of medicines including strong analgesics; and a lack of funding for caring for a dying child, with hospitals focused on cure. Nurses still struggle for professional status in Chinese culture, hampering understanding and development of multi-disciplinary care for children's palliative care services.

Lyn has always been passionate about nursing as a profession and is delighted to have been able to contribute to the development of nursing in China. Caring for children with palliative care needs, training nurses and carers to care for them and understand the uniqueness/value of what is often seen as a worthless and cursed life, has been the most rewarding thing she has done in her long career as a nurse. The majority of children she has cared for have been non-verbal and she says that to be able to provide care that enables a child to smile and enjoy life is a privilege. Being an influencer in a culture that is not her own has shown her what is possible and demonstrates the value of every human life.

The majority of children she has cared for have been non-verbal and she says that to be able to provide care that enables a child to smile and enjoy life is a privilege.

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"During this year of the Nurse and Midwife it is important to recognise the major importance of palliative care nurses. In some ways palliative care nurses are also midwives for those transitioning to the end-of-life. Nurses and nursing assistants are also the lion's share of those who work in palliative care every day around the world. Nurses deliver more palliative care than all the other health professions and are the backbone of hospice and palliative care delivery. Without nurses we could say we wouldn't be able to deliver palliative care and with it the relief of serious health related suffering."

Stephen Connor, Worldwide Hospice Palliative Care Alliance (WHPCA)

"Palliative care is a small but vitally important part of midwifery. Working in partnership with women and their families, midwives provide compassionate, respectful and empathetic care, both at the beginning and at the end-of-life. We recognise the synergies of these primarily social and spiritual events and that they impact on the wider family and community. People should have a good birth and a good death."

Gill Walton, Chief Executive Royal College of Midwives (RCM)



WAN RU NG
SINGAPORE

Nurse Wan Ru joined HCA Hospice Care, Singapore, as a palliative care nurse in 2011. Wan Ru joined the hospice after having first crossed over from the corporate world into oncology nursing where she stayed for a decade, working in the cancer unit of a tertiary acute-care hospital. She has since received further training and is now an advanced practice nurse in Singapore. Wan Ru also has an administrative role, leading a clinical team of multi-disciplinary professionals as the centre manager.

Wan Ru is currently the only advanced practice nurse (APN) working in the largest hospice home care service in Singapore, which serves over 800 patients at any one time, or about 3,000 new cases each year. At HCA Hospice Care, she leads a multidisciplinary team of doctors, nurses, medical social workers and counsellors in providing care for patients with advanced disease at home. She is primarily a clinician, and is responsible for teaching and upholding standards among the hospice home care nurses in her organisation.

Wan Ru was awarded the prestigious Healthcare Humanity Award in 2013 where her dedication to loving the dying unconditionally was noted, along with the fact that she was competent, committed, compassionate, responsible, non-judgemental and perceptive, demonstrating creative ideas in fulfilling patients last wishes. On receiving the award she said "I'm very honoured to be one of the winners for this year's Healthcare Humanity Awards. As a home hospice nurse, I have come to realise that two patients with the same diagnosis can be very different. And because of what my patients share with me about their experiences, life stories and struggles, I feel I am able to provide professional palliative care to my patients and render compassionate support to their families more effectively. As home hospice nurses, a constant challenge that we face is being able to come to terms with our patients' need to maintain personal dignity as they see it, for the time of life that they have left. Only then can we be empowered to add a new dimension to quality care that can be both effective and humane, beyond the hard science of clinical diagnosis and death."

One area that Wan Ru is particularly interested in is that of spirituality and spiritual care, providing training and undertaking research in this area. Through the years as she has developed her expertise along with services at HCA Hospice Care, her strength and passion remain with the care of terminally ill patients at the end-of-life, where humanistic tenets of dignity-preserving person-centred care are lived out.



As a home hospice nurse, I have come to realise that two patients with the same diagnosis can be very different.

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RUTH WOOLDRIDGE
UNITED KINGDOM



Ruth trained at St Thomas' Hospital, London in the 1960s before doing midwifery training. As a more senior nurse she always felt that patients with cancer suffered with pain and other symptoms that were not controlled. During that time she spent a day at St Christopher's Hospice in London – an experience which contributed to Ruth starting the first palliative care service in Kenya some 20 years later. Immediately her midwifery training was completed she went to East Africa – to work as a nurse with Voluntary Service Overseas (VSO) in Western Uganda. Little did she know before she went that she would be assisting at C-sections, giving anaesthetics, training nurses and midwives, running an Out Patient dept and a pharmacy! She returned to St Thomas's as a junior sister but it was not long before she was heading to Ethiopia to work for Oxfam twice in the very serious famines between 1973 and 1975.

Her first challenge in palliative care came in Kenya, where she was living in the 1980s. She looked after a young mother of two little boys, Nancy, living in very impoverished housing and suffering from advanced cancer of the cervix. Pain relief was impossible until she was able to get a few weeks supply of morphine for Nancy who eventually died in great pain, alone, in hospital. Nancy was her inspiration. It was immediately obvious to Ruth that there must be so many suffering from advanced cancer and receiving no palliative care – not only in Kenya but in all countries with limited health care and certainly no radiotherapy or chemotherapy then. Together with a doctor and another nurse, she wrote a palliative care policy paper for the Ministry of Health asking for palliative care to be included within health policies and clinical care. That took another 19 years to happen but meanwhile the government gave them a small plot of land in the grounds of the Kenyatta Hospital on which to build a centre. This became Nairobi Hospice in 1990. It was only the second palliative care centre in Africa, and the hospice has nurtured and trained staff over the years throughout Kenya. To support Nairobi Hospice a charity, Hospice Care Kenya (HCK) was established, which Ruth chaired for several years. HCK now supports the development of palliative care all over Kenya.

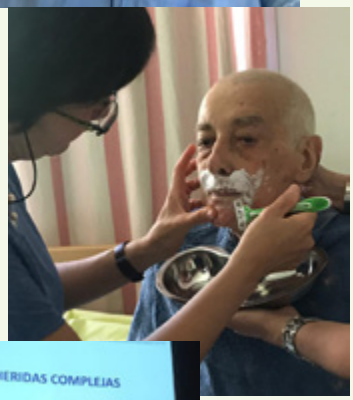
Life is about grasping opportunities and, through moving to India with her journalist husband, Ruth met someone already involved with cancer care and this presented a new opportunity. This was the start of CanSupport – a not for profit registered society delivering free palliative care - that now has 40 teams in Delhi and beyond caring for people in their own homes and supporting the families though illness and bereavement. In India Ruth realised that the training and learning for health workers was limited. On returning to the UK she formed the UK Forum for Palliative Care Overseas based at Help the Hospices, now Hospice UK. Ruth's idea of a low-cost manual for home-based care in low income countries was supported and Ruth and two doctors wrote the Palliative Care Toolkit for resource limited health settings, which has an accompanying training manual and is now available in nine languages.

Visiting Rwanda in 2004 at the time of the 10th anniversary of the genocide, Ruth met health workers to find out how much they knew about palliative care. She met one particular nurse who she thought could be a champion and Ruth sent her to the first conference of the African Palliative Care Association (APCA). A training course followed for more health workers and the first home-based palliative care service started in Kigali.

Ruth has encountered many challenges over the years, for example getting palliative care integrated into medical and nursing curricula, poverty, access to medicines, and persuading funders such as DFID (Department for International Development) to provide funding for palliative care in low and middle income countries. However she has found, through experience, that persistence can pay off. Palliative care is in many ways a nurse-led service and so many times in the last 30 years Ruth has been proud to see nurses as some of its greatest advocates. For it to be a truly global service – reaching everywhere and to the poorest and most disadvantaged – each generation of nurses needs new palliative care champions.

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CLARA CULLEN
ARGENTINA

Clara first studied and graduated in Biochemestry, yet, in her daily work, she felt she missed the personal contact with patients, so she decided to take up nursing. "I knew that nurses were the professionals who took care of patients all day long and so I intended to be an intensive care nurse, because I thought that in that unit I would fight against death." Things turned out differently when, during her studies to become a nurse, a very close friend of hers was diagnosed with cancer. She passed away two years later, after going through great pain and existential suffering. Clara was perplexed, and wondered how could this happen, was there no one taking care of those who can't be cured?

After graduating, Clara attended the First Conference on Palliative Care which was held at the Enrique Tornú Hospital, a public hospital in Buenos Aires. Clara ended up staying there seven years as she worked ad honorem, two afternoons a week, in the Palliative Care Unit.

In 2000, she received as scholarship from UICC (Union International of Cancer Care) and went to Memorial Sloan Kettering Cancer Center, in New York, to work with Nessa Coyle and to Grey´s Nuns Hospital in Alberta, Canada, to work with Pat Selmser. Those three months of work in the United States and Canada, confirmed to her that they were on the right track at Hospital Tornú although working with less resources. In 2004, she was confirmed as a palliative care nurse and since then she has been working full-time at the Palliative Care Unit of Hospital Tornú where she has been Head Nurse since 2006.

The unit has developed both clinically and educationally. Nurses work together with doctors, occupational therapists, physiotherapists, social workers, psychologists, chaplains and volunteers, all sharing the specific knowledge each one has. She sees the team as spearheading the way to make palliative care known and used throughout Argentina. So far, there is a palliative care professional in almost all of the 23 Argentine provinces, so she feels that knowledge of palliative care is expanding. She also works with the Network Information Centre (NIC) providing palliative care training on-line for nurses in Argentina. Her aim is to create the specialisation of Palliative Care for Nurses through the Argentine Association of Medicine and Palliative Care.

It was a challenge to convince the hospital community of the need for a palliative care unit. However, due to the work of Clara and the team today, there is little objection to the hospital's Palliative Care Unit and people from throughout the hospital consult them on different palliative care issues. Clara's mantra "Be patient and persevere" has paid off.

Every day Clara learns something from team members, patients and their relatives. However, by far the most important lesson she has learnt during these 22 years in palliative care, and which is still a daily challenge, has been and always will be the ability to communicate effectively with the rest of the team, the patients and their relatives and, especially, with her nurse colleagues. Always listening respectfully to others (how hard we find it sometimes!), then pondering their words and later, if necessary, answering in a loving way.

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VICKY OPIA
UGANDA



Vicky is a specialist palliative care nurse working in a remote corner of Northern Uganda - Adjumani, where access to health care can be a challenge for both local people and for refugees feeling conflict in Southern Sudan. However, Vicky says " the concept of transforming health care is dear to my heart". Vicky's own journey has taken her through training as a nurse, palliative care specialist and undertaking a Fellowship in Leadership. These skills alongside her supportive family, amazing colleagues and rich partnerships have led her to a place where she thinks that she can really make a difference, although there is still so much more that needs to be done.

Palliative care is an essential component of healthcare provision in humanitarian settings and a priority for the Uganda Ministry of Health but little is known about needs and interventions that could help to integrate such care into health systems. Uganda hosts the largest refugee population in Africa, with Adjumani District home to 250,000 refugees, mostly from South Sudan, spread over 18 settlements. Chronic disease is a huge burden to add to complex trauma, mental health challenges, loss, poverty and limited choices yet most of the focus in terms of health care remains on the acute phase and what are termed life-saving interventions.

Vicky is the focal point for palliative care in Adjumani District, works in the District Hospital and has also founded Peace Hospice, a Non Governmental Organisation (NGO) to help extend the work of chronic disease and palliative care right into people's homes, including into the refugee settlements.

Vicky and her team have partnered with many organisations including the Palliative care Education and Research Consortium, Cairdeas International Palliative Care Trust, Makerere University, ICPCN, and the University of Edinburgh and she has been able to represent the work in district, regional, national and international fora. This work has included a detailed situational analysis, training interventions for heath care workers, village health teams and family caregivers and a household needs assessment. Vicky notes that they can see a significant impact through the work that they have been doing. They now need to work to extend and scale up these crucial steps towards integrating palliative care and achieving Universal Health Coverage for those living in humanitarian and host settings.

Throughout her life Vicky has tried to look at the positives in any situation and has been determined to both develop as a person, but also to make a difference to others. She sees her role as a nurse alongside the provision of palliative care as one way of making a difference to the lives of the people where she lives. She has learnt many things throughout her career as a nurse, including the need to be adaptable and to step up when needed. Most recently she has been the lead person for the COVID-19 outbreak in Adjumani, leading a team to respond to the pandemic. When asked, Vicky says that she is now not only a palliative care specialist, but an advocate, researcher, presenter, trainer, mentor, a coach, a multi-skilled person which makes me feel 'I am an international figure' but I can also be a 'a voice for the voiceless' and can make a difference - what an amazing gift.

I am not only a palliative care specialist, but an advocate, researcher, presenter, trainer, mentor, a coach, a multi-skilled person which makes me feel I am an international figure' but I can also be a 'a voice for the voiceless' and can make a difference - what an amazing gift.

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AHMED ABU AFIFAH
PALESTINE

He is determined to increase his knowledge in palliative care nursing, and to educate other nurses in that field, to ensure that all those needing palliative care in Palestine can access it.

Ahmed Abu-Afifeh lives in Palestine in Bethlehem city and is a father of three beautiful daughters. He is currently working as the head nurse of the COVID-19 Intensive Care Unit (ICU) Beit-Jala governmental hospital. Before that he worked for four years as a senior nurse in theatres, in particular oncological surgery. He also has experience working in the adult ICU department.

Ahmed completed his Bachelor of Science in Nursing at Hebron University in 2010 and has 11 years of nursing experience. He is currently undertaking a Masters degree in palliative care, having completed H.D degree in palliative care at Bethlehem University in 2019. Ahmed has been a member of the Al-Sadeel society for palliative care since 2012 and has eight years of experience as a nurse educator, teaching baccalaureate students at Hebron and Al-Quds Universities.

As an educator, Ahmed shows his students the power of knowledge that helps in being a strong nurse and being respected by other health care professionals. As a palliative care nurse his passion is to meet the patients' needs, and to try and increase their quality of life.

He has experienced several challenges whilst developing palliative care services, including: a lack of support from health policies and education; a lack of knowledge about palliative care amongst health care providers; a lack of financial support, cancer centers, radiotherapy and medication. Another challenge is that nurses are not able to order or modify medications for patients, which means they do not always get access to medications such as morphine. He has found myths and misconceptions about the use of opioids and due to the political situation, it means that patients cannot always get permits to travel to get health care.

However, there have been various strategies introduced to try and overcome the challenges, such as referring cancer patients to Israeli hospitals for treatment such as radiotherapy, starting a palliative care higher diploma and masters in the universities, along with integrating palliative care into the medical and nursing curricula and encouraging them to specialise in palliative care. He has found that being up-to-date and scientific builds trust and strong relationships with other members of the health care team.

Ahmed has learnt how to improve the quality of life for cancer patients and how to care for the patient holistically, with symptom control, pain management and communication skills. Importantly he has learnt how to best use opioids and morphine without fear and how to utilise validated assessment tools, and ensure his practice is evidence based. His attitude to end-of-life care has changed, and he values the importance of knowledge and of working as a multidisciplinary team.

Ahmed feels that it is important to encourage experiences that promote the value of caring for dying people and the need for staff training in palliative care, which include nurse specialisation in palliative care. He is determined to increase his knowledge in palliative care nursing, and to educate other nurses in that field, to ensure that all those needing palliative care in Palestine can access it.

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"It could be said modern nursing began in a humanitarian situation when Florence Nightingale and her team of nurses went to Scutari to care for British soldiers in the Crimean War. Nurses still form the largest health cohort in the humanitarian health response.

Over 168 million people caught up in humanitarian crises require health care, and nurses who work in humanitarian health response teams may face physical danger, psychological stress and cultural differences that could challenge their beliefs. They require the ability to manage often large numbers of patients; to make independent decisions; to cope with stressful situations and to educate and develop a local health care workforce including Community Health Workers while discouraging dependency and promoting resilience.

They work with often minimal resources that challenges their initiative and creativity to design effective systems of care and make the best use of all available resources.

Midwives have an important role to play in reducing maternal and infant mortality and the provision of sexual and reproductive health services.

With an increasing number of children and adults caught up in humanitarian crises around the world we need to better prepare more nurses and midwives to meet the unique challenges these situations provide."

Joan Marston – Palliative Care in Humanitarian Aid Situations and Emergencies (PALCHASE)

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ALEX DANIELS
SOUTH AFRICA

Education needs to be a key area of focus if we are to optimise our response to health-related suffering and improve the quality of life for over 20 million children and their families globally.

Alex has worked in a range of different settings including community health, adult intensive care and facilitated grief and loss support for children and their caregivers. For the past 10 years, Alex has been working in the field of children's palliative care and these years continue to be one of the highlights of her 30-year nursing career. In 2010, Alex completed a Postgraduate Diploma in Palliative Medicine (Paediatric Elective) at the University of Cape Town (UCT). In the same year, she joined a hospital team that provided paediatric palliative care services to three Cape Town based hospitals and as the team's community liaison nurse, she focused on helping children and families transition from hospital back home. Later as the unit manager of a small inpatient palliative care unit located within a step-down facility, her energy was directed at integrating a new service into an existing public health structure. Palliative care is not yet a recognised specialty in South Africa thus both these Non-Governmental Organisation (NGO) driven initiatives came with a fair share of operational challenges and she learnt a tremendous amount from these experiences.

She has also learnt that education needs to be a key area of focus if we are to optimise our response to health-related suffering and improve the quality of life for over 20 million children and their families globally. It is essential that all health care workers be equipped with the necessary skills and knowledge so that they may offer generalist or specialist palliative care. While education needs to be geared towards health care workers, if we are to dispel the myths about palliative care, it is equally important to provide the general public with accurate information.

In April 2017, Alex joined the International Children's Palliative Care Network (ICPCN) as an education consultant and later that year as Education Officer. The primary focus of her work is education which includes both face-to-face and online training. Face-to-face training is often costly, always funding dependent and she has had few opportunities to engage with participants at this level. Most of her time is devoted to working online. The ICPCN e-learning platform is constantly expanding with over 4,800 participants representing more than 130 countries using the site. A variety of children's palliative care topics are available in several languages including English, Portuguese, French, Spanish, Serbian, Mandarin, Czech, Dutch, Malay, Russian, Farsi and Vietnamese.

Alex acknowledges that at first it was challenging to embrace the technical online and multilingual aspects of her work. However with training and support these aspects have proven to be a stimulating part of the work. Alex, who recently completed an MPhil in Palliative Medicine at UCT, particularly enjoys that her job allows her to collaborate with a range of interesting and inspirational individuals committed to improving access to palliative care education across the globe.



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DR MAHA ATOUT
JORDAN

Maha completed her PhD in children's palliative care from the University of Nottingham in the UK in 2017. She now works as an Assistant Professor at the Faculty of Nursing, Philadelphia University of Jordan. It was during her work as a nurse in a paediatric medical unit in a Jordanian hospital (2006-2010) and as a Lecturer on a paediatric clinical course for nurses across different hospitals, that she developed an interest in the subject of children's palliative care.

Unfortunately, in Jordan palliative care is concentrated on children with cancer, to the detriment of those with other illnesses, who receive no specialised care. This means, children with conditions such as cerebral palsy, end-stage renal disease and myelomeningocele are treated in medical wards or the Paediatric Intensive Care Unit, neither of which have palliative care programmes. Nurses on these wards are also overworked and prioritise biomedical tasks in line with the hospital policy, which seems to encourage professionals to focus on undertaking physical tasks rather than emotional ones. Moreover, they have neither the time nor the training to provide emotional support to children or their families, and they are therefore deprived of the psychological, emotional, and even spiritual support that they so desperately need. To add to this, there is no bereavement care available, meaning it is far less likely that parents will be able to cope after the death of their child.

Maha's experiences working with children with life-threatening and life-limiting



illnesses led to her interest in understanding communication between these children, their parents and health-care professionals. Her PhD work focused on investigating communication in the care of children with palliative care needs from the perspectives of Jordanian mothers, physicians, and nurses. She has published several papers in this field. She is also interested in investigating parental experiences of decision making at the end-of-life for children with these conditions. Currently, she is investigating children's awareness of death, a subject that is largely neglected.

Maha has presented in several international conferences and has become increasingly productive in disseminating the findings of her research. She recommends researchers to conduct further empirical studies to investigate communication with children who have non-malignant life-threatening and life-limiting



Maha's experiences working with children with life-threatening and life-limiting illnesses led to her interest in understanding communication between these children , their parents and health-care professionals.

illnesses, but also to analyse the cultural and spiritual context within which this communication occurs. It is hoped that the findings of these studies will provide the empirical evidence needed to improve clinical practice, education, and further research into children's palliative care.

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“The meaning of life is to give life meaning”.

Viktor E. Frankl

Paediatric oncology nurses offer clinical knowledge, education and support across the continuum of care. Although we cannot determine the outcome of a diagnosis, nurses have a powerful impact on the child and family experience throughout the cancer journey. Palliative care is a critical dimension of the paediatric oncology nurse’s role. The expertise, respect and compassion that is the hallmark of paediatric oncology nursing must be a constant presence throughout the trajectory of care. It is essential that paediatric palliative care education and resources are provided to nurses as they support patients and families through the end-of-life experience, which lives forever in the memories of those who love the child.

Lisa Morrissey, Chair International Society of Paediatric Oncology (SIOP) Nursing Steering Committee

DR MARIE FRIEDEL
BELGIUM



Despite many organisational and institutional challenges, Marie successfully created the first interdisciplinary and continuous PPC education programme in 2012



Since 2008, Marie has been actively involved in the development of Paediatric Palliative Care (PPC) education and research in Belgium. This has been crucial since 2014 when the Belgian law on euthanasia was extended to minors, without restriction of age, making Belgium the only country in the world to have such a controversial jurisdiction.

Despite many organisational and institutional challenges, Marie successfully created the first interdisciplinary and continuous PPC education programme in 2012, in collaboration with the Haute Ecole Vinci. Then, in 2015, she helped organise two international conferences with the FAPS (Formation en algologie pédiatrique soins continus et palliatifs) one on neonatal palliative care (2015) and another on palliative care in adolescents (2017). She also served on the scientific and organisational committees for the 8th PPC Conference of the Réseau francophone de soins palliatifs pédiatriques.

Since 2015, she has passionately committed herself to a PhD in Public Health (which she has recently completed), the first in Belgium focusing on PPC, at the Institute of Health and Society (IRSS-UClouvain). Her PhD research advocates for children's voices when they are facing life-limiting and life-threatening conditions. Currently, she is conducting the MOSAIK (Move to Open Shared Advanced Interventions for Kids with life-limiting conditions) study, which aims, through a mixed methods design, to assess self-reported outcomes for children and parents in a PPC context.

She works closely with all PPC teams in Belgium and collaborates with institutional Belgian palliative care platforms and international palliative care associations, such as EAPC and ICPCN. Within the Belgian Paediatric Palliative Care group, coordinated by Dr. M. Renard, she contributed to guidelines on PPC in Belgium, which shall be published in 2021. As a researcher at IRSS-UCLouvain, she served as principal investigator, a study, commissioned by the Fédération bruxelloise pluraliste de soins palliatifs, which found that only 1.7 % of all children admitted to a hospital with complex chronic conditions in the Brussels region between 2010-2014 had access to a paediatric liaison team, which provides both curative and palliative care. The results of this study were presented at the Brussels Parliament in October 2018 and led to a publication.

Beside her work in research, she is a Lecturer at Haute Ecole Vinci in the department of Nursing and Midwifery. There, she created several courses in ethics, paediatric and neonatal palliative care. With the collaboration of the Faculty of Medicine at UCLouvain, she has co-ordinated since 2016 an annual interdisciplinary seminar for 650 medical and nursing students to foster interprofessional collaboration by discussing case studies related to ethical dilemmas.

More recently, she is the initiator for the first time in Belgium, thanks to the collaboration with the GIP (an interuniversity and interdisciplinary group in perinatality) and Haute Ecole Vinci, of a 3-step education programme in perinatal palliative care training aimed at obstetricians, paediatricians, gynaecologists, psychologists, midwifes and neonatal nurses.

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ALEXANDRA MANCINI
UNITED KINGDOM



Alex trained as a nurse in Auckland, New Zealand. She is a Senior Neonatal Nurse with over 25 years' experience and has been instrumental in developing national and international guidelines on neonatal palliative care, including robust complex and palliative care pathways. She is seen as a leader within the field of neonatal palliative care globally, and is regularly invited to speak at national, regional and international conferences.

She works as the Pan London Lead Nurse for Neonatal Palliative Care. It is the first post of its kind and was jointly funded by the True Colours Trust and Chelsea and Westminster Health Charity. Prior to this, Alex was the Neonatal Matron at Chelsea and Westminster Hospital including providing practical and emotional support for families and staff. Alex is passionate about neonatal palliative care and is committed to raising awareness of and advocating for the development of this field of nursing. Building on her past clinical and educational experience, she raises awareness on neonatal palliative care in the UK by educating professionals in a variety of settings and strengthening working relationships between specialist palliative care services, including children's hospices. Alongside this she has helped organise the National Neonatal Palliative and End-of-life Care conference in collaboration with Children Bereavement UK (CBUK). She is regularly invited to give training and facilitates CBUK's national educational workshops, and is a guest lecturer at various universities teaching neonatal palliative and end-of-life care. Alex also developed an online course for the Royal College of Midwives which is also available globally through the International Children's Palliative Care Network e-learning programme.

Alex has published widely and was the lead editor for the recently published book 'Neonatal Palliative Care for Nurses'. In a recent blog for Springer Nature about the new book Alex said: "I am fiercely proud of my colleagues from the neonatal and children's palliative care worlds who agreed to share their knowledge and expertise of caring for babies and their families, often in extremely challenging situations. Most chapters include real case studies of babies and their families, with the nurse authors sharing their experiences with the reader. As healthcare professionals, we are continuously learning from our patients, but it is imperative that we also share these experiences with the nurses and midwives of the future as well as our more experienced colleagues."

She is committed to "Supporting nurses and midwives to shine, to be the very best they can be in a challenging landscape and provide consistent high-quality care to babies and their families"[1]

She is committed to "Supporting nurses and midwives to shine, to be the very best they can be in a challenging landscape and provide consistent high-quality care to babies and their families"

1 https://www.springernature.com/gp/researchers/sdg-programme/nurses-midwives/alexandra-mancini Alexandra Mancini Guest Blog.

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DR NICOLETA MITREA
ROMANIA

Nicoleta is actively involved in organising, supervising and teaching all the subjects in palliative care at all three levels of education: basic, advanced and specialised. She coordinates the national specialisation programme for nurses that work in palliative care services. She started her nursing career at a very young age in the paediatric hospital. December 1998 marked the beginning of an unexpected fruitful career in Palliative Nursing, when she joined the Hospice "Casa Sperantei" (HCS) as a home care nurse. Her knowledge, abilities and revolutionary style has been increasingly polished and appreciated. Currently Nicoleta leads the education and clinical practice of palliative care nurses in HCS, other palliative care services around the country and in several Eastern European countries. Nicoleta graduated from the multidisciplinary Masters Programme in palliative care in 2012 and the Medical Doctoral Studies in November 2017. Since 2020 she has been a Senior Lecturer at the University of Transylvania in Brasov. She never stopped caring for patients and is currently performing her clinical duties in the lympheodema and breast cancer care clinic. Since 2016, she has run marathons to fundraise for free-of-charge care delivered by HCS to patients (children and adults) and their families.

She was instrumental in developing palliative care as a specialty for nurses in Romania which was approved for nurses by the Ministry of Health in 2017. 77 palliative care specialist nurses graduated in 2019 and 76 in 2020.

The biggest challenges Nicoleta has faced were to get herself taken seriously not only by other professionals, particularly physicians, but also her peers. She constantly had to prove herself in terms of professional clinical competencies, knowledge proficiencies, educational, leadership and advocacy capabilities.

She believes in investing in the nurses around her, making the most of the time people have available, stepping out of her comfort zone, and going beyond limits. She realises you must accept that you cannot reach sustainable success working alone, so invest in team building.

And importantly, be you!

You must accept that you cannot reach sustainable success working alone, so invest in team building.

And importantly, be you!

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DR AYDA GAN NAMBAYAN
PHILIPPINES

Ayda is an oncology nurse clinician and educator with a subspecialty in Medical Oncology and Palliative Care since 1977. Realising the huge gap in oncology care, she moved back from the USA to the Philippines. She is the Training Consultant for The Ruth Foundation (TRF), a non-profit NGO that provides free palliative care services to the poor and palliative care training to health care workers in the Philippines. Prior to this, she worked as the Curriculum Developer for Cure4Kids, the education portal of the Department for Global Paediatric Medicine at St. Jude Children's Research Hospital in Memphis, Tennessee. She was an American Cancer Society summer fellow in Oncology Nursing at Georgetown University and a long-time trainer for the End-of-Life Nursing Education Consortium (ELNEC).

At TRF, her work includes localising the ELNEC content to fit the culture, practice and resources of the Philippines and serving as a training resource. Together, they are developing a project that will help integrate palliative care into the undergraduate curriculum, using the ELNEC course. She has also successfully implemented an institutional based programme for Advanced Practice in Oncology and Palliative Care in one of the major hospitals in Manila. In 2005, she oversaw the development and implementation of the www.Cure4Kids.org initial version of Paediatric Oncology Nursing Course and used ELNEC for the section on Palliative Care. The course was translated to Spanish and Arabic and can now be accessed globally online. As faculty at the UABSON, she implemented a clinical rotation where the students experienced what it was like to be an Advanced Practice Nurse who was a key member of the Palliative Care Team, both in the inpatient unit and in the community.



Changing the mindset of many Pilipinos that equate palliative care to hopelessness and inevitable death, coupled with a culture that considers death as bad luck, is a major challenge.

Changing the mindset of many Pilipinos that equate palliative care to hopelessness and inevitable death, coupled with a culture that considers death as bad luck, is a major challenge. Other challenges include financial factors, lack of governmental support and professional training. Although these challenges appear unsurmountable, Ayda believes that over time, they are slowly meeting them as educated, trained health care providers delivering efficient and compassionate care.

An important learning for Ayda is the affirmation of why she chose to be a nurse and what a sacred privilege it is. Although nursing has proven its professional worth, she believes that there is still much to be done. She believes that the next generation of nurses should continue the work in forging that the pivotal professional, not only in palliative care but health care in general, is the nurse.

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EMILY YAP
MALAYSIA

"Very Pain!" shouted Emily's aunt with leukaemia. She suffered in pain with no analgesic. Suffering in pain was a terrible experience and had a hugely negative influence on her aunt's physical and emotional well-being as well as the family. At the time Emily was aged 19 and her ambition was to become "a lady with the lamp" like Florence Nightingale. She hoped that she could carry a lamp to bring hope and help to patients. She went into nursing and worked for five years in a hospital. In 2006 she moved to palliative care and joined Hospis Malaysia. She completed her Graduate Certificate in Health (Palliative Care), with Flinders University Australia 2011, and a Diploma of Palliative Care through Asia Pacific Hospice Palliative Care Network (APHN) in 2012. She says "Presenting at many local and regional conferences made me proud."

She realised the importance that teaching in palliative care could make to patient care, so she wanted to be a teacher. She joined the teaching faculty of the training-of-trainers programme in Palliative Care in Sri Lanka 2016 - 2017 as part of the Lien Collaborative Programme under APHN. In Hospis Malaysia, Emily provides clinical "bedside" teaching in the community to medical students, oncology nurses, family medicine and palliative care specialist trainees. She is also a facilitator for the Palliative Care Nursing workshop.

Emily explains "Patients are vulnerable. Their voice is not strong." She sees her job as a palliative care nurse is to advocate for patients' voices to be heard by healthcare professionals. Hospis Malaysia has given her training, education, professional ethics, and enabled her to work independently. She now feels competent enough to assess, and manage, multiple symptoms including physical, psychological, social and spiritual issues. Her aim is to improve patients' quality of life. Her duty of care is understanding patients' wishes, expectations and preferred outcomes, respecting their values, needs, beliefs, cultural background and their goals of care. Her priority is in acting in the best interest of the patient and her expertise is in treating the person with dignity, not just the disease.

Emily finds working with children with cancer challenging, in particular in exploring children's understanding of their illness. Often, she uses art as a communication tool. She describes one child's drawing of a monster, who said 'leukaemia is a monster with long hands, I came to hospital to have chemo to kill this monster in my body.' She is proud to be a Palliative Care Nurse and sees her journey of experiences as adding value and meaning in life and hopes that her story can inspire other nurses.





Often, she uses art as a communication tool. She describes one child's drawing of a monster, who said 'leukaemia is a monster with long hands, I came to hospital to have chemo to kill this monster in my body.'

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PROF. BETTY FERRELL
USA



Betty trained as a nurse in the USA over 40 years ago. When, as a new graduate in 1977, she was caring for a patient with prostate cancer, her experience of his pain and desperation for help shaped the rest of her career. Betty knew that she had to do something for people like this man and help them get better pain control.

In 1980 she helped to start the first hospice programme in Oklahoma. It was there that she realised the importance of research and having the data to support the work that she wanted to do. She needed to be able to demonstrate that people were in pain and needed pain relief, and that something could be done about it.

She therefore undertook her PhD looking at patients dying at home, and this marked the start of her research and education career. Following on from this she took up a teaching role at the University of Southern California's Department of Nursing, prior to joining City of Hope Comprehensive Cancer Center as a full-time nurse-researcher. Betty still works at City of Hope as the Director of Nursing Research and Education and a Professor. It was in 2000 whilst there, that she developed the End-of-Life Nursing Education Consortium (ELNEC) aimed at advancing palliative care and building palliative care capacity in nurses. The first ELNEC course was run in Pasadena CA, as a partnership between the American Association of Colleges of Nursing and City of Hope and was focused on providing palliative care education for nurses in the USA.

Since that first course in 2001, over 30,720 trainers have been educated through ELNEC and they have gone on to train over 1,200,000 others. The course has been translated into 12 languages and taught in over 100 countries.

Alongside the development of ELNEC, Betty has been the co-chair of the National Consensus Project for Quality Palliative Care, which is a collective of all health care organisations collaborating to create clinical practice guidelines for palliative care.

Betty has been a prolific writer and researcher throughout her career and has edited several editions of the Oxford Textbook of Palliative Nursing. Her work has been recognised by many over the years and she has received many awards including: The Palliative and Supportive Care in Oncology Endowed Award from the Walther Cancer Foundation; The Distinguished Merit Award from the International Society of Nurses in Cancer Care; Fellowship of the American Academy of Nursing; and was named as one of 30 Visionaries in the field by the American Academy of Hospice and Palliative Medicine; and was elected as a member of the National Academy of Medicine in recognition of her outstanding professional achievements and commitment to service.

In her work on the ELNEC programme Betty has said "If someone you love is seriously ill you would want their symptoms well managed, support for your family, good communication, spiritual and psychosocial support and a death that respects and honours their life. This won't happen unless clinicians are trained to provide that care."

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PROF. CO-SHI CHANTAL CHAO
TAIWAN





Be brave in initiating changes and solving problems, but also involve team players.

Co-Shi worked as a clinical nurse, nursing instructor, and head nurse for ten years before becoming the director of the Hospice Home Care Programme at the Catholic Sanipax Socio-Medical Service and Educational Foundation in Taiwan. Her passion for palliative care inspired her to pursue higher education in the field. In 1993, Chao graduated with a master's degree in oncology nursing and a Ph.D. degree in nursing with a focus on hospice and palliative care from Case Western Reserve University in the United States. Upon returning to Taiwan, she resumed her role as the director of the Hospice Program and gained a full professorship of nursing at National Cheng Kung University (Taiwan) in 2002. In the past four decades, she has cared for over 600 end-of-life patients, and her work has also helped establish Taiwan's palliative care service model. She was awarded the Special Dedication Award by the Ministry of Health and Welfare in Taiwan for her tremendous contribution to the service, leadership, education, and policymaking of palliative care. In 2011, she was named "Mother of Palliative Care in Taiwan" by the Taiwan Brilliant Women Survey.

Co-Shi set a visionary strategic plan for establishing palliative care in Taiwan through policy, education, service, and research. She is one of the important driving forces behind the Nature Death Act 2000 in Taiwan, which was the first Nature Death Act in Asia. The act honoured patient's right to choose hospice and palliative care and established their right to sign a "Do Not Resuscitate" order. As a strategic and resourceful nursing leader, she understood that policy-making requires multidisciplinary collaboration. While caring for end-of-life patients and educating the next generation of palliative care professionals, she worked tirelessly to reach stakeholders involved in making the legislation. She advocated and lobbied for the act to superintendents of hospitals, administrators of health departments, and legislators from the Executive Yuan. Since the passage of the Natural Death Act, over half a million residents in Taiwan have signed the letter of intent, and the utilisation of palliative care services has also increased drastically. According to the 2015 Quality of Death Index published by the Economist Intelligence Unit, Taiwan ranked No. 6 internationally, and No. 1 in Asia. This great accomplishment would not have been made possible without Co-Shi's utmost advocacy and lobbying effort.

The greatest challenge she found of promoting palliative care was the taboo topic of "death" in Taiwan. Death was not commonly discussed among family members and even medical professionals. Through the death and dying education for healthcare professionals and the general public, Co-Shi encouraged discussion around death, increased the awareness of a "good death", and slowly changed the public's perception and mindset on end-of-life care. The shift of culture takes patience, conviction, communication, and education, and she is truly a change maker through her actions and words.

She believes that patients are the best teachers, and they continue to inspire her to improve the quality of death in Taiwan. Nurses are the key players in providing palliative care, but support from the multi-disciplinary team is essential. Her recommendation to the next generation of nurses is that to make changes takes a lot of courage, wisdom, and love. Be brave in initiating changes and solving problems, but also involve team players who will help you to achieve your goals.

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PROF REGINA SZYLIT
BRAZIL

Regina Szylit is a Professor and Dean at the University of Sao Paulo, School of Nursing. She is also a founding member and researcher of the Interdisciplinary Nucleus for Research in Loss and Bereavement (NIPPEL) and member of the International Work Group in Death, Dying and Bereavement (IWG). Her education includes a Master of Science and Doctor of Philosophy degree at the University of Sao Paulo and a Post-Doctoral Program in palliative care at Yale University's School of Nursing (New Haven, EUA).

In 1995 she played a crucial role in implementing the theme of palliative care for children for undergraduate students in various health areas, opening up the possibility of an early approach to palliative care in the education of nurses, physicians, nutritionists, psychologists and social workers. She has also developed an integrated program and process of education, research, and clinical practice aimed at improving paediatric palliative care, nursing care to families experiencing situations of death and paediatric palliative care in Brazil and Latin America.

Regina has led research on paediatric palliative care, family experience, quality of life, and end-of-life communication and decision-making. She currently leads research on suffering, grief, palliative care, and the best ways to help bereaved children and families in rural or urban areas.

In 2015 she was invited by Dr Cassiani - Regional Advisor on Nursing and Allied Health Personnel of the Pan American Health Organisation / World Health Organisation (PAHO / WHO) to create the Latin America network of Palliative Care Nursing (RIENCUPA).

The mission of RIENCUPA is to become a fundamental strategy to develop practice, management, research and education in Palliative Care Nursing, from diagnosis to disease development, the end-of-life situation and mourning. Its mission entails contributing to the development of nursing human resources in palliative care in Latin America and the generation of new knowledge, promoting changes in the national and international context. Currently, nurses from 18 countries participate in RIENCUPA.

In 2019, she defined the theme of Interpersonal Education and Collaborative Practices as a priority in the palliative care area and since then has intensely devoted herself so that this approach may contribute to the quality of palliative care in the different regions of the country.

"Palliative care nurses are the lynch pin for preventing and relieving pain and suffering, sharing expert care and kindness to improve the quality of life for cancer patients and their families at a time of crisis in the face of this devastating disease".

(Dr Julie Torode, Director, Special Projects, Union for International Cancer Control (UICC))

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IRENE TUFFREY-WIJNE
UK/NETHERLANDS



Imagine you're a nurse on a hospital inpatient unit. A 45-year-old woman with advanced bowel cancer and a poor prognosis is admitted to your ward. She has severe intellectual disabilities. She does not communicate in words (and has never done so); her comorbidities include severe epilepsy, diabetes, visual impairment and autism; she lives in a group home supported by anxious carers who have no experience of end-of-life care; and her parents and siblings think she should move somewhere more suited to her new health needs. She moans and pulls her clothing, but her carers don't know why. Would you know what to do? Where to start?

It has been Irene's mission to ensure that people with intellectual disabilities receive good care and support at the end-of-life.



She qualified as a nurse in Amsterdam (the Netherlands) before moving to London in 1985, where she spent 8 years living and working with people with intellectual disabilities, followed by 8 years as a hospice palliative care nurse. She then combined these two areas of expertise, and has spent the past two decades at St George's Hospital and Kingston University (London), doing research and development to improve palliative and end-of-life care for people with intellectual disabilities.

Her research has involved listening to the experiences of carers, families, palliative care staff, and (uniquely, certainly at first) people with intellectual disabilities themselves. She has focused on certain issues that came up repeatedly:

a) Should you break bad news? (The answer is usually "yes"). When, how, and who should do this? This has led to the development of a new model for breaking bad news to people with intellectual disabilities.

b) How can you assess and treat pain and other symptoms if your patient can't tell you about them?

c) How can you involve people in end-of-life decisions?

d) How can you make sure everyone works well together?

Irene says "All our research and good practice examples show that care can only be optimal if everyone works together.

She has written papers, books and blogs and given talks and teaching sessions in the UK and beyond. She chaired the EAPC Taskforce (now Reference Group) on Intellectual Disability, which published a White Paper in 2015.

She has chaired and is a trustee of the Palliative Care for People with Learning Disability Network (www.pcpld.org), which gives awards for good practice. She has seen many nurses make a difference, often starting single-handedly. They champion new ways of doing things, from changing the hospice referral forms (fast-tracking people with vulnerabilities) to setting up regular mutual teaching sessions between palliative care and intellectual disability staff. These nurses have often been inspired by a situation where things went really well, or distressingly bad situations that impelled them to do better.

Irene says "All our research and good practice examples show that care can only be optimal if everyone works together. This means that palliative care services must widen their multidisciplinary teams to include intellectual disability carers and professionals, and (crucially) family carers. So, if you are the nurse of that 45-year old woman, I believe passionately that you can make a difference."

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SANDRA MARTINS PEREIRA
PORTUGAL AND AZORES

For the next generation of nurses, she can only recommend to never stop caring and to never lose the ethical and human sensitivity that brought them to nursing and to caring for other human beings at the most vulnerable stages of their lives.

Sandra works as a Principal Investigator in "Ethics and Sustainability: Palliative Care" at the Research Center in Management and Economics, and is Director of the Institute of Bioethics, Universidade Católica Portuguesa, in Portugal. She graduated as a nurse and in educational sciences, and has a Masters and PhD in bioethics, a post-graduation in palliative care, and a post-doc in palliative and end-of-life care research.

The first time she heard about palliative care, she was just finishing her nursing degree and wanted to make a difference. This was in the 1990s, a couple of years after the creation of the first Portuguese palliative care unit. Soon afterwards, when she first cared for a dying patient, and his daughters, on an acute vascular surgery ward, she felt the need to have the clinical skills to provide excellent palliative care. Ever since, she has been working in palliative care in several ways: first, by integrating a palliative care approach in her clinical work as a nurse in a large university hospital; then, by promoting palliative care education at undergraduate, graduate and post-graduate levels; and now, by being a palliative care researcher and an active member of both the Portuguese Association for Palliative Care and the European Association for Palliative Care (EAPC).



Sandra lived and worked for 10 years in the Azores and still collaborates with the regional government and organisations to make palliative care more accessible for people who live in this outermost region of Europe. It is quite a challenge, but work is in progress and she is proud to see former students engaging and working actively in palliative care.

Looking back at 2010, the year that the first post-graduate course in palliative care at the University of Azores was launched, (which Sandra coordinated), brings vivid memories about the challenges that they had to embrace. The geographic dispersion and discontinuity of the nine Azorean islands; the myths and mis-conceptions about palliative care amongst healthcare professionals and citizens; the idea some nurses had that, by caring for a dying patient, they were providing palliative care already; the financial sustainability of the course. Together with other nurses (some from the mainland and others from the pioneering home-based palliative care team in Angra do Heroísmo, Terceira Island), and with a lot of resilience, creativity, hard work, patience and humor, they were able to succeed.

Since the first time she heard about palliative care, Sandra's interest, engagement and commitment have been in crescendo! She feels that she has been lucky! So many patients and their loved ones, colleagues, pioneers, students, people she loves and who have died already have inspired her in so many ways to continue to be involved in palliative care. By working in palliative care, she has learned to value more and more the most important things in life: love, vulnerability, humanity, kindness, compassion, openness and integrity. For the next generation of nurses, she can only recommend to never stop caring and to never lose the ethical and human sensitivity that brought them to nursing and to caring for other human beings at the most vulnerable stages of their lives.

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DISTINGUISHED PROF. PATSY YATES
AUSTRALIA



Patsy is the Executive Dean, Faculty of Health at Queensland University of Technology (QUT) in Brisbane Australia. She is a nurse who undertook her BA at the University of Queensland along with her Masters and PhD. Patsy has extensive experience as a leader in nursing, education and research within palliative care and nursing, and prior to becoming Executive Dean, she was Professor and Head of the School of Nursing at QUT.

She has an extensive research portfolio focusing on developing workforce capacity in cancer, palliative and aged care, and strengthening the utilisation of research in policy and practice. She has several Visiting appointments and is a Fellow of the American Academy of Nursing and the Australian College of Nursing. Over her career she has received many Awards in recognition of her work in nursing and palliative care including the USA Oncology Nursing Society Distinguished Researcher Award in 2018, The Association of Queensland Nursing and Midwifery Leaders 2018 Outstanding Achievement in Nursing/Midwifery Award, and was awarded Membership (AM) in the General Division of the Order of Australia in 2020.

Patsy is active in the national and international fields of cancer and palliative care, speaking regularly at conferences. She is the past-President of Palliative Care Australia and the current President of the International Society of Nurses in Cancer Care (ISNCC). She is passionate about nursing, cancer and palliative care and seeks to inspire and develop nurses, encouraging them to push the boundaries, and to develop as strong nursing leaders. Having undertaken the International Council of Nurses Leadership programme, Patsy is committed to developing leaders and instigated a leadership programme through the ISNCC.

"Nurses are essential to the provision of palliative care. Their holistic approach based on a sound evidence base, and their constant presence across a range of health and community settings, means they are ideally placed to ensure access to quality palliative care for all in our community."

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ZODWA SITHOLE
SOUTH AFRICA



Zodwa's passion for advocacy in palliative care began when, as a trained professional nurse, she found herself unable to help her sister when she was diagnosed with stage four cancer. She was experiencing pain and Zodwa couldn't help her. She also couldn't help patients in Clinics who complained about pain. She wasn't trained in pain management and she can still remember how scared her sister was of becoming addicted to strong analgesics and how she took her pain medication incorrectly. Zodwa also remembers the words of her sister's oncologist: "There is nothing we can do. The cancer has spread throughout your body." As a family they contacted the hospice and her sister was at peace and not in pain when she lay dying. On seeing the impact of hospice care on her sister and family, Zodwa wished she could tell more people about it. This is how her passion for advocacy in palliative care started.

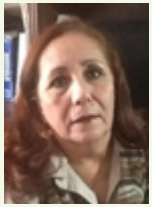
Zodwa studied palliative care when she worked at a hospice and later joined the Hospice Palliative Care Association of South Africa (HPCA) where she was their Advocacy manager. Having gained further insights into advocacy for palliative care and having cemented the principles of nursing and palliative care nursing, she began identifying influential and senior individuals from government and non-government organisations who were supportive, and pivotal, in the establishment of an Alliance for Access to Palliative Care, working collaboratively to advance palliative care in South Africa. The aim was to ensure that this care is accessible, affordable, available to everyone in South Africa. The members of the Alliance assisted HPCA to promote this goal by advocating for PC in their organisations and their networking partners. Currently she is working as the Head of Advocacy for the Cancer Association of South Africa (CANSA) and is on the Board of the International Children's Palliative Care Network (ICPCN).

At the international level, HPCA contributed to the review of the World Health Assembly Resolution of Palliative Care and the relationships Zodwa had built with senior department of health officials ensured South Africa was a co-sponsor of the resolution. The Minister of Health then established a palliative care Steering Committee to guide the development of the policy and respond to the recommendations of the WHA resolution. In 2017, the National Health Council approved the national palliative care policy which has been launched in the Western Cape and published on the Department of Health website.

Having seen inmates from one of Department of Correctional Service (DCS) facilities on TV in pain and critically ill, Zodwa approached the DCS and built a good relationship resulting in a programme to integrate palliative care into correctional facilities. Local hospices provided palliative care training and mentorship to DCS healthcare staff and training of inmates in 'home-based' palliative care. HPCA and member hospices assisted the DCS to develop a strategy for palliative care in correctional facilities.

Over the course of her journey in palliative care, a lack of awareness, lack of funding, lack of training among healthcare professionals, lack of policy and outdated policies and legislation, are among some of the challenges Zodwa faced along the way. Zodwa's advice to the next generation of nurses is to cultivate thoughtfulness and expand their abilities to lead. To advocate for their patients and their patients' families, and for other nurses. To learn what they are passionate about, believe that they can make a difference, and always do the right thing. Trust the process of your nursing journey.

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BEATRIZ MONTES DE OCA PÉREZ
MEXICO

Beatriz completed her Bachelor of Nursing studies in 1976 at the University of Guadalajara in Mexico. On graduating and passing her professional exams she worked as a surgical nurse, working as a scrub nurse for many doctors, including her father. She then went on to specialise in intensive care before getting involved in palliative care. She undertook her Diploma in Palliative Care at the Gabinete de Asesoramiento y Formación Sanitaria (GAFOS), Canary Islands, Spain and obtained a scholarship from the International Association of Hospice and Palliative Care (IAHPC) and the Sociedad Espanola de Cuidados Paliativos (SECPAL) to carry out an internship in Malaga Spain.

She has had a strong and varied career in palliative care in Mexico but also in the region. She is the representative of the International Network of Nurses in Palliative Care in Mexico. (Red Internacional de Enfermeria en Cuidados Paliativos - RienCupa), who work for the World Health Organisation (WHO) and the Pan American Health Organisation (PAHO). From 2012-2017 she was the President of the Nursing Commission of the Latin American Association of Palliative Care (ALCP).



In 2002 Beatriz founded Hospice Cristina AC, the first hospice in Mexico, and she continues to be their Director. Along with providing care Beatriz is committed to training others. In 2011 she was a finalist of the Mexico Initiative (iMX) and received an award to train 600 professionals in palliative care in Mexico. Throughout her career she has been a founding member of key palliative care organisations and has supported the work of the WHO, participating in the development of guidelines on pain management, amongst other work.

She has also been a prolific speaker and writer, contributing to books and papers on a range of palliative care and nursing issues, and is committed to supporting younger nurses to develop their palliative nursing career.

"Nurses are the backbone of palliative care and this is seen through the pillars of palliative care, making life meaningful for persons living with cancer right through diagnosis, symptom management, supportive care to end-of-life, the care never ends.

In the year of the Nurse and Midwife, we salute all nurses who with their unrelenting effort provide palliative care to people affected by cancer to improve their quality of life thus treating the person not the disease."

Naomi Oyoe Ohene Oti. Vice President, Nursing – African Organisation for Research & Training in Cancer (AORTIC)

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ROSE KIWANUKA
UGANDA

Now retired, Rose can look back with happiness and pride on what we have achieved in Uganda. Patients have a right to be pain free and the nurses who are alongside them need to ensure that this is attained. Let all nurses be empowered with palliative care knowledge.

Rose was the first palliative care nurse in Uganda and has been a trailblazer for palliative care not only in Uganda but regionally and internationally. Following an experience in hospital at the age of eight, Rose was determined to train as a nurse, as she wanted to be like the nurse who had cared for her, who was smart, gentle and caring. She trained as an Enrolled nurse at Nsambya School of Nursing in Kampala, later upgrading to a Registered Nurse. She then undertook a Diploma in Palliative Care with Makerere University through Hospice Africa Uganda (HAU), and a Degree at the Aga Khan University in 2015. She was full of enthusiasm and ideals as she began her nursing career, and it was during her training that she first cared for a patient who was dying, which greatly impacted on her decision to work in palliative care.

She was recruited to work with Dr Anne Merriman in 1994 following the first palliative care course organised by Dr Anne in 1993, to help start the first palliative care service in Uganda, and as there was no palliative care training in the country then, she had to go to the UK and the Netherlands to train. She worked at Hospice Africa Uganda for many years, both in clinical practice and education, being a role model for other nurses and health professionals in palliative care. It was during this time that Rose, along with others in Uganda, worked with the Ministry of Health to enable nurses trained in palliative care to prescribe oral morphine in order to make pain control accessible and available to more people in the country. Thus, Rose was one of the first nurses able to prescribe in Uganda.





Now retired, I can look back with happiness and pride on what we have achieved in Uganda. Patients have a right to be pain free and the nurses who are alongside them need to ensure that this is attained. Let all nurses be empowered with palliative care knowledge.

After 15 years at HAU, Rose moved to a new role to work for the Palliative Care Association of Uganda (PCAU) as their country director in 2006. When joining PCAU Rose was the sole employee and now, years later, PCAU has its own accommodation with offices and 15 employees, and is recognised by the Ministry of Health as the lead for palliative care within Uganda. She is a strong advocate for palliative care utilising her clinical, educational, mentorship and leadership skills in all that she does.

Since those first early steps, Uganda now has palliative care programmes in >95 of the 112 districts and nurses are able to prescribe oral morphine, which is free of charge to the patients. Rose has been invited to present at numerous fora including at the UN and the World Health Organisation. She has and continues to inspire nurses in Uganda and around the world, and her commitment and passion for palliative care continues and is evident to all who know her.

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"The exacerbating pain that gave sleepless nights and sent patients with cancer and others with such chronic conditions into shock and some even to death has been saved by the Palliative Care Nurses.

Palliative Care Nurses have played a role of innovative service that is rightfully needed to allay pain. Prescription of oral morphine, which had solely been the role of Medical Officers, is that role that the Palliative Care Nurses have taken on very effectively, bringing hope in hopeless situations and a smile on tearful faces.

It is a service given at all levels of healthcare wherever the affected patients are being cared for, including at home and in the community, where family members are involved and care is holistic and people centered.

Maximizing Palliative Care Nurses' contribution requires that they are properly deployed, valued and included in policy development and decision making."

Catherine Odeke Nursing Now Uganda

JULIA JOHNSTON
CANADA



Seek out practice in areas with strong nursing leadership. If none exists collaborate with your local, national, and international colleagues to create it. There is strength in our numbers.

Julia Johnston entered the Nurse Practitioner programme in 2002 after practicing as a Registered Nurse in clinical, education, management and leadership roles for 14 years. She was a Nurse Clinician for a hospital wide programme which also enabled her to gain programme planning and evaluation competencies. She was fortunate to have worked in oncology, medicine and intensive care settings. This experience provided her with a continuum of learning, helping and feelings of uncertainty. She saw at times the failure of her knowledge and the healthcare system to meet the complex needs of people living with and dying from illness, and the people who loved them.

Julia had wonderful mentors in her workplace who encouraged and supported her to pursue post graduate education. She focused on a Masters preparing her for a Nurse Practitioner (NP) role focusing on adult palliative care. At the time there were no other palliative care NPs looking after adult patients who could preceptor her for her clinical placements.

Fortunately, the discipline of palliative care values interprofessional education and cross professional learning so a palliative care physician colleague volunteered to act as her preceptor and she was able to collaborate with NPs from other clinical disciplines and a Clinical Nurse Specialist (CNS) from oncology for the professional practice competencies of the APN/NP role.

She has been on the Board of Directors for the national nursing Hospice Palliative Care Nursing organisation in positions of regional representative, Secretary/ Treasurer, President now Past President. Through this she co-chaired the development of national standards of Hospice Palliative Care (HPC) nursing practice which have been used internationally as the basis for HPC nursing standards around the world.

In addition to clinical work, Julia has had numerous opportunities to provide leadership as a NP in palliative care at the local, regional, provincial and national level, including: developing a palliative care program for a cancer centre where none previously existed; working with a regional health authority to collaborate with multiple stakeholders to develop a region wide palliative care program which has resulted in more primary and specialty care providers and teams developing competency in the provision of palliative care for their patients and their families and communities.

Challenges in palliative care are well documented and are often homogenous across organisations and nations. Julia is particularly attuned to how scope of practice barriers negatively the timely provision of high-quality hospice palliative care in Canada and around the world. To this end she is engaged with her professional associations to champion increased scope of practice for Nurses and other healthcare providers to ensure palliative care is available to all who want and need it.

Julia believes that palliative care is foundational for all clinical practice including the medical oncology floor where she began her nursing career in 1998. Her palliative care nursing career has deepened her belief in the value of nursing to the health outcomes and lives of our patients, communities and nations. She has learned perseverance and the skills of collaboration and advocacy to use her voice to champion those who are weakened or have died and can no longer speak and to advance her beloved profession.

She recommends the future generation of nurses focus on the determinants of health for their profession including addressing gender and pay equity, access to education, ensuring nurses have the tools required to make an impact, and the regulatory authority and autonomy for the Nursing voice to be heard. Seek out practice in areas with strong nursing leadership. If none exists collaborate with your local, national, and international colleagues to create it. There is strength in our numbers.

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STELLA VERGINA
INDIA





Throughout her career she has demonstrated leadership within nursing and palliative care, receiving numerous certificates of appreciation and recognition.

Stella has over 34 years' experience in nursing. She initially trained as a nurse in the Armed Forces at the Military Hospital Secundrabad and Jhansi, being commissioned as a Lieutenant in 1986. After leaving the Army in 1992 she worked in private hospitals and then worked for the Ministry of Health Libya and the Ministry of Health Sultanate of Oman. She then worked in the Government medical college Kozhikode in Kerala from 2006 until she retired earlier this year.

Stella first started training in palliative nursing in 2007 when she undertook a basic certificate course in palliative nursing, and has followed this with various palliative care trainings including the ELNEC and EPEC courses. She undertook a National Fellowship in Palliative Nursing in 2015-2016 and is a trainer for both the ELNEC and EPEC courses. When working at the Medical College Calicut she provided nursing care and psycho-social care to patients and empowered the patient and family, providing a specialized service in lymphoedema, colostomies, and malignant and other chronic wound care.

Throughout her career she has demonstrated leadership within nursing and palliative care, receiving numerous certificates of appreciation and recognition. In 2020 she was awarded an international award for excellence and leadership in palliative nursing. Within India she has presented regularly at the Indian Association of Palliative Care conference, both as part of the faculty but also through abstract submission. She has also had the opportunity to present at several other international conferences and has taken a lead role in training nursing and medical professionals, volunteers and campus students in palliative care throughout India. She also conducted workshops to empower and educate families and patients about lymphoedema care, care of the bedridden patient and communication skills.

She is recognised in India as a leader, both in palliative care and in nursing, and has been a member of the Central Council for the Indian Association of Palliative Care, taking a lead on nursing issues. Stella is committed to building capacity for palliative care in India for nurses, but also for health professionals in general, and has been involved in national initiatives to develop training programmes such as the development of a facilitator guide/ training manual for training doctors and nurses under the National Programme in Palliative Care.

Her many achievements within palliative care include: the compilation of the modified manual for the basic certificate course in palliative nursing; participating in the national consultation for creation of palliative care curriculum for undergraduate medical and nursing students, and for training physicians; being the lead author on several chapters and training modules, including the module on nursing issues for the one-year National Fellowship in Palliative Medicine and Nursing; and part of the core committee developing the curriculum for the basic certificate course in community nursing and palliative care in Kerala.

Since retiring from her government post, she has been involved in delivering online training and case discussions for doctors, nurses and nursing students, organised by a collaboration including the Indian Association of Palliative Care, Pallium India, Cipla training centre, Lien collaborative for palliative care and others.

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ABOUT THE INTERNATIONAL CHILDREN'S PALLIATIVE CARE NETWORK (ICPCN)

The International Children's Palliative Care Network (ICPCN) is the only 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 that all children living with a life-limiting or life-threatening condition and their families will have seamless access to palliative care in order to alleviate serious health-related suffering and enhance their quality of life.

Our mission is to achieve the best quality of life and care for children and young people with life-threatening or life-limiting conditions, their families and carers worldwide, by raising awareness of children's palliative care among the public, health professionals and policy makers; advocating to governments and international organisations for the global development of children's palliative care services; expanding the evidence-base for children's palliative care; and sharing expertise, skills and knowledge with our global network of members.

We operate in five key areas: Communication, Advocacy, Research, Education and Strategic Development

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ABOUT THE WORLDWIDE HOSPICE PALLIATIVE CARE ALLIANCE (WHPCA)

The Worldwide Hospice Palliative Care Alliance (WHPCA) is an international non-governmental organisation focusing exclusively on hospice and palliative care development worldwide. We are a network of national and regional hospice and palliative care organisations and affiliate organisations.

We believe that no-one with a life-limiting condition, such as cancer or HIV, should live and die with unnecessary pain and distress. 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.

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ABOUT THE INTERNATIONAL ASSOCIATION OF HOSPICE AND PALLIATIVE CARE

The vision of the International Association of Hospice and Palliative Care is towards a world free from health-related suffering. Its mission is to serve as a global platform to inspire, inform and empower individuals, governments and organisations to increase access and optimise the practice of palliative care.

The IAHPC has a variety of programmes and projects including its advocacy programme, travelling scholars and fellows, the Global Leaders in the Advancement and Development of Palliative Care (GLAD) programme, the Global Palliative Care Database, the consensus-based definition of palliative care, competencies in undergraduate education, opioid price watch and palliative care essentials. We also have a range of resources on palliative care on our website.

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Incorporated in the USA
Charitable organization No 76-0674392

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