

Because I Matter

Letters from women affected by serious illness and palliative care to decision makers



World hospice & palliative care day

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Introduction

61.5 million people worldwide experience serious health-related suffering which could be addressed by palliative care. Unfortunately, less than 10% of those that need palliative care can access it and 42% of the world's countries have no palliative care services at all. We know however from the Lancet Commission on Palliative Care and Pain Relief that an essential package of palliative care in low- and middle-income countries costs about \$3 per capita.

On World Hospice and Palliative Care Day, the voices of those who are directly affected by palliative care are being heard. The theme 'Because I Matter' reflects that everyone deserves and has the right to the quality care that they need. There is always something that can be done. So why is the availability and access to palliative care so woefully inadequate and inequitable for people who need it worldwide? Why are so many people's lives and stories not being heard by those who could make a difference to the care they receive?

This report consists of the open letters of six extraordinary women from Australia, Bangladesh, India, South Africa and the UK to decision makers who can influence access to palliative care. These women are directly affected by palliative care through living with serious illness themselves or being parents of children with serious illnesses. They are working to make a difference to the lives of other adults and children who are affected. They aim to encourage greater understanding of and commitment to ending avoidable suffering and making palliative care available for all as part of the move towards Universal Health Coverage.

As countries move towards Universal Health Coverage, the voices of those affected by serious illness must be heard to ensure equitable coverage of palliative care for those who need it.



Dr Tedros Adhanom Ghebreyesus
Director General
World Health Organization
Avenue Appia 20
1202 Geneva



13 October 2018

Dear Dr Tedros

I am writing you an open letter to thank you again for taking the time to meet with me. I was so impressed by your knowledge and understanding of palliative care. It was good to talk to someone who understood and listened so carefully to my experience.

As you know, I was told when I was 17 that I would probably live for 5 more years. Last week I had my 25th birthday! Palliative care has been crucial in enabling me to live well for these years and to live with purpose and meaning. Last week I was also given an Honorary Masters at the Open University for my work with the Sexuality Alliance! I sometimes shake myself and wonder how I got here but I am so thankful for the support and encouragement I have received from my health care team in the UK through the wonderful NHS, my hospice support and most of all my family and friends.

Anyway, I am just writing to express my gratitude for all the work WHO is doing to support palliative care including as part of primary health care and as part of Universal Health Coverage. The meeting in Astana to review the Alma Ata declaration will be so important as it is crucial that palliative care is integrated within primary health care so that everyone who needs palliative care around the world can get it. This is the only way we can achieve Universal Health Coverage.

The work of WHO on the subject of palliative care, including the indicators within the General Programme of Work, are encouraging. Yet, like many areas, palliative care development is not getting the resources it needs either from national government health budgets, donor governments or international agencies. I hope in my lifetime to see that change happen especially given the evidence we now have from the Lancet Commission on Palliative Care and Pain Relief that an essential package of palliative care costs just \$3 per capita in low and middle income countries. It is a moral imperative to stop avoidable suffering.

I hope to meet you again one day and thank you again for all your work and for reminding the world that people like me do matter! Happy World Hospice and Palliative Care Day.

Kind regards,
Lucy Watts MBE

Mr. Mohammed Nasim, MP,
Honorable Minister of Health & Family Welfare.
People's Republic of Bangladesh

13 October 2018



Dear Minister,

I am writing this letter to you to draw the attention of the government of Bangladesh, and your ministry, to the severe lack of access to care for people living, dying and suffering from incurable life limiting diseases like cancer. This specialized care is well known globally as "Palliative Care". My personal focus is the alleviation of immense suffering of approximately 19,000 children with cancer who need this care in Bangladesh. There are few resources for paediatric palliative care, despite the fact it is a cost-effective intervention. The commitment of your ministry to these children could have a huge impact on their, and their families, lives.

Me and my family's personal experiences of such suffering is inspiring me to write this letter to you. I lost my three year old son to cancer after witnessing his immense suffering for 8 months. My son, Ayman, was born on 19th April, 2012 and left us on 3rd January, 2016. Although he is no longer with us, we are continuously reminded of the pain and suffering he went through. Now, long after losing my son and after meeting many other families and children with experience of this journey of suffering, we know that even though we could not cure him, we could have alleviated much of his, and our, suffering if we had access to palliative care for children in Bangladesh. As a very small initiative after his departure, a few other bereaved mothers and I have taken this responsibility to make people aware of the importance of palliative care to stop avoidable suffering in Bangladesh.

Decision makers and policy makers of a country have great influence on society and can make palliative care available in the community for families like mine. With greater understanding and commitment to the importance of palliative care, such care can reach out to more children and families even in resource constrained countries like Bangladesh.

Dear minister, you are also a father so I hope you understand.
Your understanding and support of palliative care matters because these human souls also DO MATTER. Let's end this suffering.

Sincerely yours
Shayema Shafiz Sumy

The Right Honourable Penny Mordvant
22 Whitehall
London SW1A 2EG



13 October 2018

Dear Minister

I am a 57 year old woman with severe life-limiting disease. I am fortunate in having been supported by an expert hospice and palliative care team locally (Barnsley) for several years which has enhanced my quality of life and functional ability enabling me to engage in life optimally in the context of my disabilities and health problems.

Even within the UK many are not so fortunate. Outside the UK things are even more difficult for individuals with life limiting, often extremely painful conditions. Many individuals with life limiting conditions in low and middle income countries (LMICs) are not even able to access basic pain relief. As highlighted in The Lancet Commission on Palliative Care and Pain Relief there is also a disproportionate number of individuals with serious life-limiting illness in LMICs. An essential palliative care package for these countries described by the Lancet Commission would cost only \$3 per person.

I feel passionately that palliative care is a basic human right and that as a developed country we should be specifically supporting palliative care services in LMICs. Having experienced the reality of life-limiting illness and severe pain made bearable only by appropriate pain relief I speak with the voice of lived experience. Furthermore, prior to ill-health retirement I was a consultant paediatrician working in paediatric oncology and have also seen at first hand the difference good quality palliative care makes to children. Many of the individuals without adequate palliative care and pain relief in LMICs are children who are suffering unnecessarily when even basic palliative care would make a huge difference to their quality of life.

The UK has reduced its overseas aid commitment on health at a time when many LMIC health systems are in desperate need. Of that aid, there is no allocation committed to palliative care despite the UK's expertise in this area and proud history in its development. October 13th is World Hospice and Palliative Care Day. In recognition of that I am asking you to commit to the UK Government increasing support for palliative care worldwide as part of progress towards Universal Health Coverage and identifying aid specifically to support palliative care projects for children to provide them with basic pain relief and palliative care to facilitate improved quality of life.

Yours sincerely
Helena Davies

To Shri. Jagat Prakash Nadda
The Union Minister for Health & Family Welfare
Ministry of Health and Family Welfare
New Delhi, India

13 October 2018



Respected Shri. Jagat Prakash Nadda,
Please help 2.21% of Indian population to live. Not just exist; but to live with dignity and to grow to our potential. And to be useful members of the society, contributing to it.

My name is Ashla. After injuring my spinal cord in an accident 8 years back, I am living with quadriplegia. I use a wheelchair to move around. For the initial four years, I moved from hospital to hospital trying different treatments. Then I moved to Pallium India [3], a national organization which provides palliative care. Since then, I am a full-time volunteer at Pallium India. Here, I receive all the care which I require on a daily basis to function. I work as an executive assistant to the Chairman of the organization and also as a counselor at the paraplegic rehabilitation center in our organization. My life is an example which shows how palliative care can improve the quality of life of a person with life limiting condition.

Census 2011 has revealed that over 26.8 Million people in India are suffering from disability. This is equivalent to 2.21% of the population. A considerable portion of this is acquired later in life. And it is also estimated that the total number of people who need palliative care is likely to be 5.4 Million people a year [4]. Palliative care is available only to less than 2% of the needy. As proved by the palliative care movement in the state of Kerala, providing pain relief and palliative care in a cost-effective model with active community participation is possible. I believe every single individual in this country has the right for an opportunity to contribute to the society in his/her own way. Usually, a person with a life limiting condition is no longer given that opportunity. They are often pushed to the margins and forced to exist there until they die.

Chapter 5 of the Rights of Persons with Disabilities law which is passed in 2016 ensures "barrier-free access in all parts of Government and private hospitals and other healthcare institutions and centres". However, this is not implemented completely though this can be achieved without significant cost. Hence, I request you to kindly take necessary actions implement this by 2020.

Yours sincerely
Ashla Rani

Senator The Hon Anne Ruston
Assistant Minister for International Development
and the Pacific
PO Box 6100
Senate, Parliament House
Canberra ACT 2600



13 October 2018

Dear Minister

As an Australian citizen, I am also writing to you as a woman living with younger onset dementia and someone who advocates and works globally and nationally to ensure the 50 million people currently living with dementia globally, and the projected 152 million people with dementia by 2050 receive the care that they need. This includes the more than 425,000 people living with dementia in Australia.

My own diagnosis of dementia came as a shock to my family and friends, especially as I was only 49; a married working mother of two teenage sons. As a result of the poor treatment I received and the stigma I experienced personally, and that is still being reported to me daily, I co-founded a global organization called Dementia Alliance International, which is a registered charity in the USA, but represents people with dementia from 47 countries. This organization was founded in part to ensure that the voices of people living with dementia worldwide are heard at every level. As a retired trained nurse, and someone who talks with people with dementia and their care partners almost every day, I know that an important part of good care is access to palliative care. I'm well aware that one day I may need it too, and I may need my pain managed which is notoriously under-treated with people with dementia. I'm very aware as my condition progresses I will have swallowing difficulties and breathlessness; I already have swallowing difficulties. Therefore, I understand well the importance of developing advance care plans so my family know how I want to live and be cared for if I no longer have the capacity to explain. I was actively involved in developing the recently updated Advance Care Directives in South Australia.

Lack of access to palliative care is a human rights issue worldwide, including for people with dementia. 42% of countries have no hospice and palliative care service and it is estimated that less than 10% of people who need it can access it. All around the world, we see people regularly physically or chemically restrained, harmed or abandoned, and in many countries, they are entirely let down by the health care system which fails them in their care right through to the end of life. Even in countries where palliative care is available, it may not be accessible to people like me with dementia. As you are well aware,

Australia has just commenced a Royal Commission into the Aged care system in Australia, due to continuing reports of systemic abuse and very poor care.

Australia is one of the few countries which has a national dementia strategy with strong inclusion of palliative care and as such we could and should be leading the global charge for good access to palliative care for people with dementia worldwide. As countries move towards Universal Health Coverage, I hope that you, as the Assistant Minister for International Development and the Pacific, will join with us to recognize and act upon the unrelieved serious health related suffering experienced by people with dementia worldwide and show leadership in making palliative care available to all. We know that an essential package of palliative care costs just \$3 per capita in low and middle income countries and I ask for your personal support to make this happen through the Australian government's international policies and programmes.

Yours sincerely
Kate Swaffer

Minister Aaron Motsoaledi

Private Bag X9070

Cape Town

8000

Dear Minister Aaron Motsoaledi,

I would like to start my letter by congratulating you on the drafting of the National Policy Framework and Strategy on Palliative Care for South Africa. I am so proud to have been part of the National Steering Committee, and I am looking forward to the implementation of the policy, to ensure access to palliative care for each and every South African.

Minister, I am a social worker by profession, and last year I have obtained the post-graduate Diploma in Palliative Medicine from the University of Cape Town. I am also a very proud person with a disability, and a passionate advocate for universal access. I work for the Hospice Palliative Care Association of South Africa as Disability Mainstreaming Coordinator. I have further had the life changing opportunity to receive palliative care after my motor vehicle accident 24 years ago. For these reasons I believe that I can share the positive influence that palliative care has had on my life.

After my accident 24 years ago, I have received palliative care from a dedicated and compassionate group of palliative care practitioners, and dear Dr Motsoaledi, if it wasn't for the palliative care that I have received, I would not have been the person that I am today! I would not have had the quality of life that I have, to pursue my dreams, to manage my own health and to be gainfully employed.

Minister, I have had numerous adversities and some very painful difficulties in my life to overcome, including a spinal cord injury, bladder cancer and diagnosis of an auto-immune disease, but palliative care strengthened my fundamental being, taught me tenacity and guided me to acceptance and fulfilment. It taught me how to manage my own health, but mostly palliative care guided me to reach my optimum quality of life.

The palliative care team were the compassionate earthly angels that were always there for me, on the ready to provide care, to manage my symptoms, to lead me to be the person that I am today, to guide me towards acceptance and ultimately, to reach my optimum quality of life.

The question that I am posing to you today, Minister, is why isn't palliative care available to each and every person in the country should they need it?



Palliative care should be available to all and should be an integral part of Universal Health Coverage. I can and will continue to inform people and advocate for palliative care and every individual's rights to access palliative care daily, but Minister, you are the person holding that key to unlock access to palliative care for all.

You are the one that can ensure that palliative care gets the much-needed funding and attention to be readily available to all. You are the person that can declare that health and allied professionals cannot proceed to be independent practitioners, if they did not have the necessary and required palliative care training.

Palliative care is the tool that can and will save this country millions of Rands in healthcare provision! Life limiting, and life-threatening conditions would be managed, and patients, their families and carers would not have the need to access health care for micro management of every symptom. They would be aware of and educated on their condition, they will have access to pain medications, they would be mindful of challenging situations and how to manage these. They would have the physical, emotional, spiritual and total care that we all deserve.

Palliative care has, can, and will assist me and all my fellow South Africans to live a full, meaningful life till the day that we die.

Please make palliative care possible, available and accessible to all SA citizens.

We matter, and we have the right to palliative care!

Sincere greetings.

Petra Burger

Call to action

- Ensure an essential package of palliative care for adults and children is integrated into Universal Health Coverage worldwide (See Lancet Commission on Palliative Care and Pain Relief).
- Ensure palliative care is integrated into primary health care.
- Ensure that people who need palliative care can access it irrespective of where they live, their condition, their age or their disabilities.
- Ensure that adequate funding is allocated by national governments, donor agencies and international agencies to enable the provision of palliative care for those who need it.
- Enable the voice of people with direct experience of serious illness and palliative care to be heard during decision making processes on policies and programmes that affect our lives at the local, national, regional and global level.
- Ensure that palliative care is a compulsory part of the curricula for all health professionals and allied professionals such as social workers.

Why?

Because I matter!

About World Hospice and Palliative Care Day

World Hospice and Palliative Care Day is a unified day of action to celebrate and support hospice and palliative care around the world.

Voices for Hospices is a wave of concerts taking place on World Hospice and Palliative Care Day every two years. It takes place on the second Saturday of October every year and Voices for Hospices takes place on the same date every two years.

World Hospice and Palliative Care Day is organised by a committee of the Worldwide Hospice Palliative Care Alliance, a network of hospice and palliative care national and regional organisations that support the development of hospice and palliative care worldwide.

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Thanks to Open Society Foundations and The Joffe Charitable Trust for their kind support of The WHPCA's direct stakeholder projects.

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