



Trustee reframing palliative and hospice care day Public Health Palliative Care

Introduction

Palliative care has done an enormous amount to relieve the physical, social, psychological, and spiritual suffering of people who have a terminal illness over the last 60 years. The achievements are immense, and millions of people have been helped. The help has gone beyond symptom management in the above four areas, improving communication throughout medicine.

Despite everything that has been achieved, the possibility for further development outweighs what has gone before. Unfortunately, palliative care still excludes more people than it includes.

The challenges faced by Hospices in trying to address this inequity alongside challenging funding models and a changing NHS are not easy to balance. However, the practice of public health palliative care is a system wide, complimentary strategy that seeks to resolve them through taking a population-based approach. Recognising the role of community driven care alongside specialist palliative medicine.

There are three major challenges which mean that hospices exclude more people than they include. These are: -

1. Lack of equity of access to hospices and palliative care teams in general.

Most people seen by hospice teams have a diagnosis of cancer. This varies somewhere between 50 and 95%, depending on the service. Yet only 25% of the

people who die have a diagnosis of cancer, and not all cancer patients who die see a hospice team. What happens to the other 75% of people who die? Chronic illness accounts for 80% of all deaths. There is no evidence to suggest that people with cancer suffer more than those with chronic diseases, especially when people have multiple diseases.

2. Focus on needs and symptoms rather than health and wellbeing

The practice of palliative care has assumed that resolving needs and symptoms, using professional services, will mean that the patient will have a good quality of life. However, meaning and value, and good quality of life, is to be found in relationships with the people we know and love in the places we know and love. This is called social ecology. To help people, not just the person with the illness but also those who support them, live well right up until the end of their lives, direct attention must be paid to help nourish the relationships to people and place. Professionals are important but do not occupy the same place as the people held most closely in our hearts. Social ecology is found in relationships with the communities in which we live. This is where the main focus on improving health and well-being, which can be present even in the context of a terminal disease, needs to be.

3. Lack of a population-based model of bereavement

The NICE model for bereavement has three tiers; specialist support; volunteer and peer support led mostly with the support of professional services; and support of family, friends, and communities. It is estimated that only a small percentage of people need specialist bereavement support, yet 100% of people need the love, laughter, and friendship of those around them. And yet hospices rarely have a population-based model of improving bereavement support in communities by communities, so that everyone who is bereaved can have access to the type of support they most need.

These three issues, present because of the nature of the historical development of palliative care, means that most people who die, AND those closest to them, do not get the kind of support that we would all like at the end of our lives.

It does not need to be like this.

The practice of public health palliative care, developed over the last 25 years, solves these challenges through taking a population-based approach and through paying equal attention to building communities of support and through management of disease, using the new public health methodologies of prevention, harm reduction and early intervention. Hospices can truly become embedded in their community, serving the whole population rather than being limited to just those with a cancer diagnosis, through the practice methods of public health palliative care. This includes the development of compassionate communities and participating in the compassionate city charter.

Public health palliative care is now part of specialist training for all palliative care consultants. It is also part of the revitalised Ambitions Framework for Palliative and End of Life Care. Ambition 6 is communities are prepared to help. All hospices will be assessed to see whether they sufficiently engage in developing compassionate communities.

It is vital that trustees of hospices understand the complimentary nature of a public health palliative care strategy and its central importance in the future provision of hospice services in a complex and evolving system. We want to work with hospices to support them in balancing the provision of specialist care alongside a public health palliative care strategy.

Finally, there are significant implications for fund raising. Traditional hospice fund raising models have relied on large donations and bequests to support the often-meagre NHS funding. As funds from the NHS increase with the new funding model for palliative care, there will be an expectation for hospices to provide equity of access. Furthermore, there is good historical precedence for the use of micro fundraising, through small donations of large numbers of community members.

Compassionate Communities UK Trustee Training Day

Compassionate Communities UK, leaders in the field of public health palliative care, offer a training day for trustees to help them understand the developing changes to the role of hospices. The training is a single day covering 6 topics.

1. The palliative care blind spots –
The number of people excluded from hospice services is greater than included. Equity, structural vulnerability is all part of why this exclusion takes place. A shift from an illness model of care to a health one is needed. Equity of care for bereavement.
2. Biology of compassion, social relationships, and kindness as a fundamental part of human evolution and biology. The science that backs up this strategic approach
3. Public health palliative care – a social as well as a medical model. What does help mean? Who benefits from help? Kinship, all my relations
4. What are the structural components needed to be able to provide palliative care for everyone? Clinical care is much more than symptom control. Integration with community is key.
5. What are the barriers and what are the opportunities? What does it mean for fundraising and publicity?
6. Compassionate Communities and Cities – power relationships, community development, death, dying, loss, and care giving is everyone's business.