Is public health the new frontier?

Keynote Speech
At Princess Alice Hospice’s Annual General Meeting on 13 September 2016
By Professor Allan Kellehear

Introduction:

Professor Fiona Ross CBE, Chairman of Princess Alice Hospice:

I’m really delighted to introduce Professor Allan Kellehear to you. Allan is a medical sociologist. His work is around end of life care, but particularly looking at some public health approaches to the end of life. In Allan’s very distinguished academic career, he’s had professorships at La Trobe in Australia, and at Bath, at Middlesex, and now at Bradford, and Allan’s work on compassionate communities inspired us in our new five-year strategy development.

Professor Allan Kellehear:

So, as you’ll probably know within a few minutes, I’m Australian, and although I’ve been in Britain for ten years, it hasn’t changed me that much, so I still say I’m pretty much the same. I was the first professor of palliative care in Australia who was non-clinical, and I established the public health movement, both Australia and worldwide, and I’ve been here for ten years now, working closely with the different governments in Britain.

The public health movement in palliative care is nearly 20 years old. When I come to places like this, I still get some flashbacks about the early days. I remember after we had… the government funded our first public health palliative care unit in Australia, I went to the first palliative care conference, and the president of the palliative care association in another state ran up to me rather breathlessly and said, even before the ink had dried on our service agreement, Allan, you know, you can’t prevent death. Note to self.

And the other thing is that, you know, you’ve upset a lot of people because the government is taking a portion of the palliative care funding and putting it into health promotion, and that money is really ring-fenced for our palliative care beds. You know, I didn’t think palliative care was about building beds. I thought it was about care of the dying, caregivers, and the bereaved.
So, it was news to me even then that we’re in the historical act of building palliative care beds forever. If you said that in accident emergency, oh, you got some of your money to educate people to wear bicycle helmets and seat belts, that will shrink our casualty departments. What a terrible thing. And the poor cardiologists would say, don’t educate the public about diet and exercise, less patients for me. Similar kind of process.

We’ve come a long way, though, I think, and increasingly more hospitals are embracing the public health approach and understanding what the public health approach is really about, because at the end of the day, it’s the same as the palliative care approach. It’s about care of the dying, and actually the aged, and caregivers, and those experiencing loss and grief, not just bereavement.

So, I’ve been asked here to talk for half an hour about what that public health approach is and tell you a little bit about its current developments, if this works. Let’s see how this goes. There we go. So, what are the key facts we have to remember when we’re listening this evening? The first one is dying is a social, psychological, and spiritual experience with a medical dimension, and not the reverse. Now, I’m sure most of you know this and take this for granted, and of course the budgets which you allocate are allocated this way, aren’t they? The other thing that you have to bear in mind is that most of the time that dying and grieving people spend is actually outside of the service of professional care.

Less than 5% of the time that dying people experience is with a doctor, or nurse, or social worker, or complimentary health therapist. 95% of the time, even when they’re in the room in your hospice, 95% of the time they spend alone, or with a TV set, or with family, or with friends, or with animal companions, and way before they become inpatients, many of them are working, or living normally, just like the lot of you at the moment, not seeing a doctor or a nurse.

That’s what dying is really about. It’s in the community. That’s what grieving is about; in the community. That’s what caregiving is about. A very small part occurs in direct service provision.

Remember that big picture, folks. We all get lost.

Finally, National healthcare budgets everywhere have stalled or gone backwards. Every year, the NHS believes that it doesn’t have enough money … It’s true. It doesn’t have enough money, and it’s not the only one. Australian healthcare budgets have the same problem. Canadians have got the same problem. The Americans are a bit different. We won’t go there for a moment.

40% of people who attend primary care services don’t need to be there. They’re there because they like the conversation, and the company with their GPs, or they have an acute self-limiting condition, which will go away if they’re not seeing anybody. 40%. So, you’re thinking about 40% of the primary healthcare budget going on people who need company, or who’ve got conditions which would just go away, and it doesn’t matter what study you read from what country, it’s always roughly that figure, 40%.

We need an alternative model for how we care for each other, and the models with the greatest success are from places like Canada and Australia, big countries with small populations that can’t
put a GP on every street corner, and they can’t certainly put a palliative care physician on every street corner. So, now we’re starting to look at those models.

What are the key challenges? Well, first of all, inpatient models, building a hospice on every street corner is geopolitically unviable, not possible, and even if it was, I spent some years in the Republic of Moldova, and they built a lovely hospice, 20 minutes up in the mountains behind Chisinau. No one goes there. Why don’t they go there? Well, most old ones can’t afford a car. Those who can afford a car can’t afford the gas. Those who can afford the gas can get to the hospice but can’t drive back, so nobody uses it.

The cancer focus is not generalizable. The palliative care tradition began with cancer, but life’s changed considerably since then, and aging is a major challenge, and in fact cause of death is not actually cause of dying. You can get a cause of death in a maybe metastatic cancer, large cell, lung, widely disseminated, but actually the previous 12 months might have to do with their COPD as well, may have to do with the fact that they’re frail, may have to do with the fact that they also suffer from dementia.

Co-morbidities. That’s how people die. What ultimately kills them doesn’t describe the previous 12 months. Those days are gone. Then there’s the inadequate addressing of co-morbidities and mortalities. People think, ah, people are dying, terrible thing. Actually, you know what, there’s only one terrible thing, the people who are dying, who live with life-limiting illnesses for one year, six months, six years, people who live with anxiety, depression, social isolation, social withdrawal, social rejection, job loss, suicide.

All of these things happen to lots of people living with life-limiting illnesses. All of them, if not all of them are amenable to prevention and harm reduction. We can do something about this sooner, rather than later. We also have an elaborate model of continuity of care. I’ve already mentioned cardiology and accident-emergency. Every medical speciality has a health promotion speciality.

They don’t until the disaster happens, right? They act earlier. You wear your bicycle helmet, you wear your seat belt, you wear your condom, not all at once, but generally speaking we understand in medicine that that plays an important role alongside surgery and pharmacotherapy, except in hospice. New kids on the block, slow to recognise, and that’s what we’re doing now, catching up with the pack.

Then there’s the question about psychosocial. I love psychosocial. When I first came to [unclear] 20 years ago, people said, oh, we’ve taken care of all this stuff. Psychosocial care. You know what the problem with psychosocial is? Always more psycho than social. Therapist pops up there, as soon as you’re bereaved, her counsellor.

I don’t want a counsellor that will bite my leg. I want a counsellor. I want friendship. I need support up there, and the bulk of people are the same. Ideas about community have been primitive. Community is where we get our volunteers, where we raise our money, where we tell them where the local hospice is. It’s not about how people actually do things, you know, partners, with their own experience and expertise.

That’s where the public health idea is very different, and we need to ensure that end of life care is consistent with the other approaches that I’ve mentioned, and all the other medical and healthcare
specialities. We need to recognise loops for service provision. Yes, we need hospices, yes, we need cardiologists, yes, we need casualty departments, but we need the rest.

We need to move away from thinking about everybody who comes before us as a patient.

I go to a conference, you come with me. At dinner, I have fish and chips, battered fish and chips. You might say to me, good choice, Allan. The second night we go out, I eat battered fish and chips, you'll say, oh, Allan, you love your fish and chips. The third night I go out and have fish and chips, dead silence. Fourth night, we go out and I have battered fish and chips, one of you, you won't be able to stop yourself, will say, Allan, this is bad for you. You will die if you keep this up.

That’s health promotion from peers. Not my doctor, not my nurse, my friends, my colleagues. We support and educate each other around health promotion. Imagine a world in which death, dying, and loss was like that.

Imagine such a world. We’re close. We have to think about building social capital in the community. Yes, it’s great to raise money for health services. Build another hospice, but remember the wealth that we really have to build is in our workplaces, in our churches, in our schools, the people who will become our patients, we need them better off sooner rather than later. We don’t need to do panic control at the end.

Palliative care, holistic palliative care, a lot of that, a lot of panic. Psychological, social, spiritual, and physical care. Let me translate that for you. Doctor, nurse, social worker, counsellor. Pastoral care, chaplain. If I’ve got an end, I’ll bet you can imagine a professional to throw at it. Public health holism. Workplace, the pub, the club, the street. Advertising, the newspaper, the radio. Schools and university. My yard. Your car. My place. Your place. That’s holism.

And we need to begin working with communities, not on them. Communities are not patients. They’re colleagues. We need to work with them. We need to know what it’s like to be an engineer or a concert pianist, or at least know that not everyone’s the same. We need to take being working class seriously, being South Asian seriously, being Afro-Caribbean seriously, being gay and lesbian seriously, how that changes the way in which we experience suffering and loss.

So, we need to think about prevention, harm reduction, early intervention, through community development, not direct service provision. Community development, public education, very important. We need to be educated about the public, the public needs to be educated. The swap. Remember at school when you collected cards and used to do swap? It’s still with us. You do it with experience.

Palliative care people have got an enormous amount of experience in death, and dying, and loss, but don’t think for a minute that the community doesn’t have its own experience. There are many men and women and children have their own experience which you can learn from. It’s a trade. Most parts of the healthcare system have understood this. We’re new kids on the block, and slow to learn.

So, we need to develop our public health principles first alongside our institutional priorities. We need to work with the social and cultural sectors. We need partnership models. We need the mainstream of dying as a life and living issue. We’ve got to stop people from thinking about death,
dying, and loss as a hospice thing. I got into a cab recently. All the time, I’ll say. What line of work do you do? Oh, I work in hospice.

That either kills the conversation, or I get stories of institutional dying. People don’t think about suicide, children breaking their neck falling off a tree, or in car accidents. Grieving people that come back from war. Paralympics. Now, sure, it’s all death and dying, it’s all [inaudible], it’s all grief and loss. This is all our work. This is our work, folks. But the community thinks it’s cancer, and dying in a hospice. We’ve got a big job on our hands.

So, this is where creating compassionate communities becomes important. We first developed it in Australia in the 1990s. As a major experiment in India, compassionate city Kozhikode continues very well. It spread to the UK in the mid-2000s. We have new developments in the European Union, the continent as it’s now called, in the late 2010s, and there are recent developments in Canada and the US. Canada in particular is rapidly developing compassionate communities, and it has its first compassionate city of Burlington, Toronto, just this year.

In the UK initiatives, we had the introduction of the compassionate community. Public Health England has run six trials of compassionate communities run out of hospices.

The Scottish Partnership for Palliative Care have adopted this as their main policy within Scotland, and of course the new Ambitions Framework in Palliative Care just recently published ambition number six at the community scale, and it’s the public health approach.

We’ve also done major collaborations with churches, temples, businesses, schools, and workplaces. We have great policies being developed in different parts of the country. There’s been a shift towards community sector support and away from palliative care-based volunteers. I always said the best model for volunteering in palliative care is making volunteers run the hospice, and make the trustees the volunteers. Who wants to change then, folks?

And we’ve also created cultural media sources of death education. We’ve been mentoring family carers for other family carers. We have developed the Compassionate City Charter, which is a charter that cities actually sign up to. These are the kinds of things that they agree to do.

Bradford City has agreed. We have a compassionate city. Leeds is in talks at the moment … and Edinburgh in talks … and Birmingham in talks. Londonderry in Northern Ireland has passed… their local authority have passed a council motion saying they will adhere to the Compassionate City Charter, Frome in Somerset.

We have Seville in Spain who signed up to be a compassionate city, Burlington of course in Canada, Gais in Germany, and there are several other European cities that are coming on board just this year actually, and it would be lovely to have Edinburgh and Birmingham. They’re quite big cities.

And they all agree that they will work with communities as partners, chamber of commerce, major faith groups, to develop policies for people in their care. They’ll be presenting the programmes. Hospices, and nursing homes will be encouraged to have community development programmes, and I understand you’re developing one. More power to you.
Museum and art galleries have to have annual exhibitions, and there will be an annual peacetime memorial parade. You know, you’ve got Veteran’s Day. People walk down the road and remember the war here. The overwhelming majority of people don’t die in wars, folks, they die in peacetime, and we don’t memorialise that, and that’s got to stop.

So, compassionate cities is going to have a peacetime memorial, so people can bring their losses into the public gaze, and not have them hidden away in homes by [inaudible] medals. There will be local government incentives and reward schemes, art competitions, story competitions, and we will relook at our support programmes for homeless and those in prisons, traditionally older populations.

What have been the outcomes so far? We’ve done some evaluations. It’s looking good. The one that the NHS likes to jump on is the drop of 30% in emergency service, GP service, and 24-hour crisis lines. I love that one, not that I have a vested interest or anything. I’m sure that their heart’s in the ideological right place, but they seem to focus on the bottom line, like universities these days.

The important outcomes are that palliative care goes back to a modern public health message. Health and death and dying is everybody’s business, everybody’s business, not just hospice. Everyone. Cab drive, school teacher, students, lawyers, everybody. You all have a role to play in stopping me eating fish and chips four times in a row. You all have a role to play to help support me when my dog dies.

There’s been less ignorance, less fear, more care, and more control, and more compassion based on the kinds of all the different methodologies we have used so far in the [inaudible] way to assess these things. There have been policy changes in Scotland, Australia, and in England, and there have been major practice changes in those countries.

We have the 5th international conference, which will be held in Canada in 2017. It was held in England two years ago, a year ago, 2015, and in Southern Ireland two years before that, so it moves around. The international movement around this is quite big, ironically led by patients. I don’t think you’ll find a sociologist in science, but introduction, and there’s been an establishment of an international association of clinicians and academics as Public Health Palliative Care International. You can see that on the website if you go fishing for it, and there’s the further reading.

Is public health the new frontier? Yes, it is. Should you embrace it? Yes, you should. Will it fix everything? No, it won’t, but it’s a good way to doing that. But at the end of the day, it’s our friendships and our relationships with each other which count, informed by a good health professional.

George Burns, US Comedian. When he turned 99, he called a press conference. That’s what Americans do when they turn 99. A whole bunch of people like you turned up, and he boasted that every day of his adult life, he smoked a Cuban cigar, drank a large glass of red wine. One of the journalists said, well, what does your doctor say about that? To which George replied, nothing, he’s dead!

Thank you very much.