SOCIAL CARE AT END OF LIFE IN THE UK

My perspective is that of a registered specialist palliative care social work practitioner employed by an independent hospice. I distinguish between social care (soziale Arbeit) and social work (Sozialarbeit). Against an overall background, I highlight what I consider three main current drivers in social care, namely the ‘compassionate communities’ approach; changes in UK law and the need for an evidence based approach. I briefly explain how they play out in the hospice world and here in one UK hospice in particular.

There is a revolving debate about who is in charge of social care at the end of life, and thus is responsible; who delivers it and thus takes the care; and who does or does not receive it and therefore knows best. Social workers like to pitch their tents in many places, as commissioners, practitioners and service user advocates. And they seek those prolific platforms that require passionate front line practitioners, experts, researchers, teachers and trainers and those who know how to campaign. Given their skill set, social workers are destined to fulfil all those roles. However, specialist palliative care social workers, i.e. those who exclusively operate in the field of end of life care, are small in number. 400 members are currently registered with the national Association of Palliative Care Social Workers. Given the approximately 250 hospices in the UK and those being the most common employers of specialist palliative care social workers, this workforce is probably less than a 1000 strong. And yet there is a lot to get on with; all in the context of a funding gap for social care in general. The parallel key concerns here are how overall social care is to be paid for and how the quality of social care can be improved and sustained. Yet, by the time this debate gets round to end of life care scenarios, the brunt of the debate has often already played out elsewhere, the steam evaporated. Those promoting end of life care have to shout loud to get attention; those promoting social care at the end of life shout even louder. Although the term ‘holistic’ care is well used, especially by hospices, it is the medical and nursing care with the much needed focus on physical symptoms that is immediate and tangible and arguably easier to focus on. Social care is woolly in comparison; it involves as many things as there are to maximise people’s independence, quality of life and dignity. For social care at the end of life to be truly effective, it is ideally situated early on in the trajectory of illness. Yet this is where it lacks profile: people in the UK, including health and social care professionals, currently often only talk about death and dying when there is no choice but to do so; late on in the process; too late. Those early opportunities to plan ahead are missed and social care needs at the end of life, such as those generated by the normative experience of anticipatory grief and bereavement, may become unnecessarily exaggerated; prompting a social care response often close to that of an emergency service. Various current UK campaigns recognise this and call for timeliness in the provision of social care:

* Ambitions for end of life care (National Palliative and End of Life Care Partnership)
* The route to success in end of life care – achieving quality for social work (National end of Life Care programme)
* Advance Care Planning (Dying Matters Coalition)
* Caring for the increasing number of dying people with dementia (Dementia Friends Campaign)
* Caring for family carers (Carers UK)
* Combating funeral poverty (Funeral Poverty Alliance)

All those campaigns can be framed by three key drivers. Firstly there is the public health approach to end of life care. Driven by leaders such as Prof Allan Kellehear and Dr Julian Abel and to be delivered ultimately by compassionate communities this approach is music not only to social work ears: for local communities to galvanise, support one another, with professional formal carers as instigators and supporters of those more informal care networks, such as families, is desperately teasing. Who wouldn’t agree that to be surrounded by loved ones, supported by friends and neighbours in one’s own home is bound to meet one’s social care needs such as good company; practical support and personal care much better than any formalised care? This approach is at once deeply social in its nature as well as most difficult to deliver where social problems are rife: families are fraught especially when death and dying is added to the mix and don’t want to or cannot care; people do live isolated lives and may not have a supportive community or a home or may not even want one. And many argue the obvious namely that the type of community required here is hard to come by. Meanwhile Hospices are deeply challenged by this step change. Their traditional approach has been to directly provide ‘bed’ and ‘building’ based expert care; their success is often still inextricably linked to the communities’ fondness of that special place of care. And so good is the care that one criticism of it, and a blatantly obvious one at that, remained largely unchecked for decades. Namely hospices long stand accused to be “too good to be true and too small to be useful” (Douglas, Colin. "For all the saints." *British Medical Journal*, 29 Feb. 1992, p. 579. *Academic OneFile*, Accessed 24 Apr. 2017) and indeed to this day hospices still reach only the chosen few, mostly white middle class population. For hospices to truly demonstrate compassion across the entire spectrum of the diverse communities they serve will be a new era. One UK hospice has responded to the call for compassionate communities by aiming to evolve into a ‘Hospice without Walls’. The endeavour to take the care to people where they are and to teach others to care as well as prioritise direct care provision by themselves, has led this hospice to run nationally unique projects such as the end of life ambassadors program reaching out to those working in care homes (6 steps programme), with the homeless and with those in prison.

Secondly, changes in UK law embrace some of social care’s most basic tenets, or so it seems. The new Care Act 2014 has given family members who care for a loved one a legal entitlement for an assessment of their social care needs in their own right. Whether this will actually change the plight of carers remains to be seen. The Act also rebrands the previously named ‘vulnerable adult’ into an ‘adult at risk’; making the prevention of adult abuse as statutory as the protection of children had been for decades. A subtle change in language permeates this Act; arguably one that is more respecting of vulnerability; more empowering of people. Another fairly recent change in law was rung in by the Mental Capacity Act 2005. This Act is designed to protect and restore power for those who lack mental capacity. More seasoned than the Care Act but nevertheless similarly lacking in implementation, the Mental Capacity Act may become the most important in this century as far as social care generally is concerned. From an end of life care perspective this Act has walzed in gently yet caused significant cultural changes particularly for the hospice world: this somewhat blissful world of tender loving care provided by selfless doctors, often with strong religious and here Christian backgrounds, supported by well meaning volunteers, usually of white middle class background, is now gradually being re-framed as a place like every other: a place of care where adult abuse is a key issue requiring vigilance from all staff and volunteers involved no matter what their individual cultural background and attitude may be; a place of care where legal safeguards need to be applied as soon as the cared for is deemed as lacking mental capacity to make decisions for themselves. While the Care Act stands out for its careful wording, the Mental Capacity Act has yet to find the right tone in some places. In particular the ‘Deprivation of Liberty Safeguards’, added in 2007, have shaken patients, their families and care providers. The ‘Safeguards’ are meant to protect those who lack mental capacity to decide where they want to be cared for. Whereby professionals used to be able to keep hold of people under common law because it was collectively or authoritatively deemed good for them, they are now required by statute to assume mental capacity in all cases; to formally prove any lack of mental capacity and if found lacking then there has to be a named decision maker on behalf of the individual. And any care provided in such case has to be in the person’s ‘best interest’. This previously commonly and over used phrase of ‘best interest’ has turned from slang into legal terminology. Professionals up and down the country are still using it without realising this, rendering themselves vulnerable to liability; later to be argued in court. Overnight, the ‘Safeguards’ in particular rendered hundreds of people in need of requiring formal assessment of their mental capacity. As a result the system in charge of processing this has ground to a national halt. A prioritisation approach has emerged futile as it parks care providers at odds with the law, even causes them to act unlawfully, if they were to follow it. Those at end of life are deemed in the least urgent category. A major law review is now under way in relation to the ‘Safeguards’. Meanwhile residential care homes, hospitals and hospices are enduring the chaos usually associated with implementation gaps.

A third theme permeating end of life care generally is the need to evidence outcomes. It is outside the scope of this article to consider the complicated area of outcome measures in detail. However, one way of measuring outcomes is increasingly given attention not least by the Care Quality Commission, the UK body inspecting social care services: the patient story. Huge attention has been given to this across recent key publications about end of life care. We know that end of life care has made that difference when the patient says so. What difference others want it to make depends on who is asked: the UK government, for one, seems to have at last let go a little bit of its obsession with the ‘preferred place of care’ as an outcome measure. The “*Five Priorities of Care*” (Leadership Alliance for the Care of Dying People 2014) and last year’s “*Government response to the Review of Choice in End of Life Care*” reaches much deeper*:” Our commitment is that every person nearing the end of their life should receive attentive, high quality, compassionate care, so that their pain is eased, their spirits lifted and their wishes for their closing weeks, days and hours are respected. We shall ensure that all the needs of the dying person – spiritual, physical and familial – are provided for in a way that is as that person and those closest to them wish them to be”* (Ben Gummer MP Parliamentary Under-Secretary of State for Care Quality). In terms of social care the areas of spiritual care and bereavement care have definitely been given ‘commitment’ here even if this is still outside any formal commissioning arrangement. Two trends are emerging: firstly spiritual and social care are increasingly overlapping with social workers being put in charge of spiritual care, at least as far as hospices are concerned. Emotive debates are evolving to ensure this isn’t yet another trick in making limited funding go as far as possible but also to establish whether this is a sign of increasing secularisation in society. The latter is hugely significant in a movement as steeped in religion as the hospice movement. Secondly, bereavement support has become the hallmark of the role of the specialist palliative care social worker; the emphasis here is on support in its basic sense; on listening, not counselling. Listening is a core social activity. In relation to bereavement it should not be professionalized under any circumstances according to expert Dr. Colin Murray-Parkes. Yet in the UK, where people may struggle to listen to each other, listening to the bereaved often requires highly qualified professionals to be available or to train volunteers and harness their guts to do it. Social care professionals once more become the gatekeepers of what should be done by everyone.

In the particularly UK hospice referred to throughout this article social care is promoted as everyone’s business; to a degree. Namely the hospices’ services and strategies are based on a 4 tier model of psychosocial assessment and intervention (F Hearn et al (2008) *Re*-*emphasising the social* *side: a new model of care”*. European Journal of Palliative Care, Vol.15 (No.6). pp. 276-278. ISSN 1352-2779). Level 1 is where all health and social care colleagues operate. Namely, all are expected to have an awareness of social care issues and the ability to record and to escalate those appropriately - usually to the hospice social worker. Level 2 describes the vast area of social care intervention for those with one or two well defined issues such as problems with achieving the chores of everyday life including the inability to walk the dog or inability to deal with debts. Bereavement needs may sit on this level too. Level 2 is crucial from a strategic point of view as it offers unique opportunities for hospices to track trends and identify gaps in services as well as potential partnerships; this level could be the gateway point where decisions are made whether a service is provided directly by the hospice or whether it is instigated by the hospice, along the lines of the compassionate communities approach described above. This hospice has just started a person centred leadership pilot project where hospice staff actively use eco mapping in their first encounter with patients to determine their network and use it to its full advantage for that patient, rather than come in as the experts who take over, however well meaning that may be. This hospice is also about to start another pilot project where trained listeners are to be located in a local General Practice. This project is beautifully ambitious in that it hopes to release the GP’s (Hausaerzte) from the burden of listening to the bereaved; an activity so important yet not one doctor tend to have time for. The project is in line with the growing profile of ‘social prescribing’ and based on a wealth of evidence from Scotland where a similar approach showed a reduction in GP appointments used by the bereaved and potential to reduce prescription medication being issued by the GP’s as the listening emerges as therapeutic in itself. Level 3 is where social work begins and focuses the organisations to protect this resource to do what it is best to do, rather than keep brimming with business at level 2. Level 4 takes social work to its more senior level of leadership and consultancy.

In conclusion this article does not pretend that specialist palliative care social workers are in charge of social care at the end of life in the UK but they like to play their part. Success here rests on sensible law and policy, always has done; and also on hospices to keep an open mind to significant cultural change. 2017 is looking good: much of the very recent changes point towards the ethos of social work being intrinsic to new law and policy. And the commission into the future of hospice care, which culminated in 2013, has suitably challenged the hospice movement. It is early days to determine whether those developments will make a felt difference to those in need and in receipt of social care at the end of life in the UK.