HEALTH AND WELLBEING BOARD PAPER
FORMAL PUBLIC MEETING

Report of:	Greg Fell
Date:	26th September 2019
Subject:	Towards an intelligence-led End of Life strategy for Sheffield
Author of Report:	Eleanor Rutter
	07917 240200

Summary:

Questions for the Health and Wellbeing Board:

- Does the Health and Wellbeing Board accept that a comprehensive end of life approach, including community and civic elements is most likely to deliver best outcomes for Sheffield? If so, would the Board sponsor a workshop to consider whether Sheffield should become a 'Compassionate City' and how best to progress that?

- How will the Board help to engage and enable leaders from within communities and neighbourhoods?

- Can Board members give their individual organisational commitment to an integrated intelligence function to deliver this work?

- Does the Board support further development of a strategy based on the six national ambitions with the addition of a dynamic intelligence core?

Which of the ambitions in the Health & Wellbeing Strategy does this help to deliver?

Ageing and Dying Well: Everyone in Sheffield lives the end of their life with dignity in the place of their choice.

Who has contributed to this paper?

Dr Sam Kyeremateng – St Luke's Hospice

Dr Anthony Gore – Sheffield CCG

John Soady – Sheffield City Council, Public Health

Louise Brewins – Sheffield City Council, Public Health

Towards an intelligence-led End of Life strategy for Sheffield

1.0 SUMMARY

This paper describes the importance of taking a holistic approach to the 'end of life' for all of Sheffield's citizens as opposed to a more narrow, medical view of 'end of life care'. Rather than discussing medical causes of death it explores the common elements of any life coming to an end. As such it suggests that if all people affected by a death are to have their physical, psychological, social and spiritual needs met in the most cost-effective way possible we must develop and integrate our specialist and generalist palliative care services alongside compassionate communities and a civic approach to support and improve the end of life experience.

The paper highlights how many important questions regarding the end of life are currently unanswerable in spite of the considerable time and effort put into collecting data in different organisations nationally and across the city. It describes how close we are to completing a comprehensive, joined up approach to intelligence which can drive forward the change that is needed in this area.

2.0 HOW DOES THIS IMPACT ON HEALTH INEQUALITIES IN SHEFFIELD?

Everybody dies regardless of social class, ethnicity, sexuality or any other defining characteristic. Not everybody can expect to have their needs met optimally by the current system in Sheffield. There is a mounting body of evidence that suggests that access to appropriate support at the end of life is dependent on clinical diagnosis, age, social class and ethnicity amongst other things. Not enough is yet understood about those inequalities in Sheffield.

By taking an intelligence-led approach to the change suggested in this paper, we will be better able to understand the inequities in the current system and how we can focus our efforts on reducing them.

Towards an intelligence-led End of Life strategy for Sheffield

1. Introduction

In December of 2018 Sheffield's Health and Wellbeing Board (H&WB) signed up to nine ambitions in its revised strategy. One of those ambitions was to ensure that everyone in Sheffield could live the end of their life with dignity in the place of their choice. This paper starts to explore how we might achieve that ambition. It focuses particularly on the concept of the 'end of life' (as opposed to 'end of life care'), includes the importance of that not just to the dying person, but to all of those involved and left behind, and describes how we might develop and use high-quality intelligence to transform Sheffield into a place where everyone involved in a death has the best possible experience.

1.1. What is the End of Life?

Around 1% of the population die each year. In Sheffield, in 2017, that equated to 4,991 people. Of equal importance to this paper is the fact that in excess of 577,789 Sheffield residents are on a pathway to death at any given time.

It could be said that dying is easy, "simply an out-breath … and no more in-breaths"[1] – the challenge comes in what happens around the terminal breath: in the time before and after that breath, and as experienced by the people around the dying person.

Whilst each death is unique, all have common factors. A better understanding of those common factors can help us to prepare optimally in order to get the best possible outcomes for individuals, the bereaved, care staff and the city.

1.2. What it isn't

Death is an emotive subject. The term 'End of Life' is likely to conjure up a clear image for most people: a palliative care nurse, a 'do not resuscitate' order or the death of a high-profile celebrity. The volume of charitable activity in relation to the end of life is testimony to how strongly people feel (but may also indicate how hard people find it to understand or deal with their own emotions in this area, preferring to channel their distress into something that feels positive).

These are all important elements of our current end of life care system, but do not encompass a whole-population approach to the end of life and can offer an unhelpful narrative by either conjuring up a complex, highly-medicalised image of the end of life or a sanitised version which fails to acknowledge and therefore prepare for some of the more challenging aspects.

2. Background

2.1. What we know

Many discussions about the end of life include a description of causes of death. This paper intentionally avoids that approach, as describing pathology can often, perhaps inevitably, draw the

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[1] Sarah Malik. Specialist Information and Support Nurse. Haematology, Oncology, hospice care and helpline nursing.

reader into a medical model of thinking. That is not to deny the importance of medical interventions in some deaths, but if we are to develop a city-wide approach to preparing optimally for the end of every life, it is important to understand firstly the type of needs that arise around the 'edges' of that single, terminal breath.

2.1.1. The 'Edges'

The edges of a death can be viewed as having two dimensions; one is human, the other, time.

In the case of a predictable death, it can be seen clearly that a dying person will have physical, psychological, spiritual and social needs which all end at the point of death. What is less well documented is that there are layers of people around the dying person who will have similar needs which also continue in the immediate aftermath of the death and potentially, well into the future.

How great those needs are and how well they are met will determine the overall impact on the individual, the bereaved, the wider community, professional care staff and society. If that impact is the best possible, we can move beyond something which may be considered to be a good death to making Sheffield a good place to die.

2.1.2. Types of death

Whilst the cause of death can contribute to the experience of dying, it is perhaps more helpful to think of deaths within a few important categories:

- Sudden or predicted
- Adults, children or perinatal
- Physiological, pathological or traumatic (i.e. due to old-age, premature (and preventable) causes or accidents)

2.2. What is the problem?

2.2.1. The triple gap

The myriad of challenges currently facing the health and social care system are often characterised according to three, key gaps, namely: gaps between available and required financial resource, best possible health and wellbeing outcomes and those currently experienced and consistent, gold-standard care quality and the variable standards currently delivered. Nowhere exemplifies these three gaps better than the current end of life care system.

Whilst many people do have a good experience of death in Sheffield, some do not. Sometimes people's final stage of life is not lived in a way they may have hoped; that can often involve multiple hospital admissions in the twelve months before death. This puts them in one of the most expensive parts of the system where it can be most difficult to meet their needs, particularly social, psychological and spiritual. In 2017/18 there were 2,748 people on primary care, palliative care registers in Sheffield who experienced a total of 2,678 A&E attendances and 2,884 potentially avoidable hospital admissions, with an associated cost of £9.5m.This is not a financially sustainable model of care and the growing population only serves to increase that pressure.

Anecdotal evidence suggests that that some groups of people get a better experience of care and support at the end of life than others. This avoidable gap represents an inequality in both quality and sometimes even quantity of life.

Examples of poor care at the end of life are too common. People in Sheffield are not guaranteed to get the best possible experience. This can take many forms; one prominent example is the recent CQC report of care for older people which raised as an issue the poor integration of services to support people at the end of life. In addition to variation of quality within our current model of care, questions are being raised in the professional community about our fundamental approach to end of life care. 'Over-medicalisation' cannot only affect the quality of the end of a life detrimentally, it can actually shorten life and, perhaps more importantly, hide death away inside institutions thus removing the essential learning experience from the wider community that death is a normal part of life.

2.2.2. Leadership

There is great energy for change in Sheffield. Leadership, so far has tended to come from people working in the specialist, palliative care area, perhaps a reflection of the fact that it is they who are most comfortable talking about the end of life and how that might best be supported across the city.

The effort that has brought us to this place is immense. We must guard against discounting that because of the part of the system from where it has come. We have preconceived ideas about a 'spectrum' of care from community-based, self-care, through social care support and primary, medical care to specialist, bed-based, palliative care. It is easy to attach to that 'spectrum' the labels 'good and cheap' at one end and 'bad and expensive' at the other.

| Community-based self-care | Community-based primary and social care | Specialist, bed-based, palliative care |

A city that offers a good end of life experience to all has no spectrum, but a fully integrated model (see figure 1 below) which recognises that different people will require different support and ensures their needs are appropriately met.

That said, if our aim is to enhance, support and integrate the more specialist services, with our community structures we need to identify experience and leaders from within communities and help them to engage others more broadly with the process and experience of dying. It could be suggested that the absence of community leaders from this current collaboration might indicate an absence of such people, but the volume of charitable activity that happens in this area would suggest that is not case. What is more likely is that our current medical-model of dying, and 'top-

5

down' approach to bringing about change, is excluding experienced and passionate leaders from within our communities.

2.2.3. The bereavement journey

Bereavement is associated with worse physical and mental health outcomes and increased use of medical services. Estimates in Scotland suggested it could add £23.3m per year in additional hospital bed days alone[2] and yet the primary need (often depression and loneliness) could better be described as failures in social support systems. Loss, the stresses and strains of caring and 'compassion fatigue' do not affect only one, key person, nor do they only begin at the time of death. The experience of caring and circumstances of a death can either worsen or mitigate the impact of suffering a bereavement.

Unlike death, which occurs only once, loss and bereavement is something most people experience multiple times in a lifetime. A good experience is not just a worthwhile end in itself, but prepares an individual for subsequent occasions and ultimately their own death.

In Sheffield, not enough is known about the experience of care and loss at the end of life and anecdote suggests too many people are impacted more negatively than would be the case if communities were better supported.

2.2.4. Over medicalisation

Many examples of really good end of life experiences come from hospices. That has led us, perhaps understandably, to assume that the frequency of poor care would lessen if more people had access to specialist palliative and/or hospice-based care.

Whilst all people need to have their physical, social, psychological and spiritual needs met as they approach the end of their lives, all people do not necessarily need a doctor, a specialist team or an in-patient bed in order to do that. The origin of even the best palliative care is from within our medical system and thus is built on a medical model of need. There is always a risk, therefore that medical solutions will be sought to problems which may potentially have different, and more effective, social solutions. Our increasingly medical approach to death has, over recent years moved it into medical spaces. This has itself had a negative impact by hiding death away, removing its 'normality' and making it something people don't understand. In turn people 'miss out' on the learning experience of watching elderly grandparents, family friends and perhaps neighbours die; all helpful preparation for when death comes even closer to them.

2.2.5. Intelligence

Strategic planning within the end of life system in Sheffield could be described as 'data rich, but intelligence poor'. That represents a 'lose-lose' situation whereby staff in single organisations can spend a great deal of time and energy collecting data, whilst at the same time system leaders are not able to answer the most basic questions, which are essential if the system is to be transformed. For example:

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[2] Stephen AI, Macduff C, Petrie DJ, et al. The economic cost of bereavement in Scotland. Death stud 2015; 39: 151-7.

- How many people in Sheffield have a good death?
- Who gets a good death and is that fair?
- Could death be better if services were structured differently or if society viewed it differently?
- Can we make dying more cost-effective?
- What happens to those left behind after death?

These questions need to be answered if appropriate change is to be made. That requires appropriate resource to be committed to turning data into intelligence and in turn, high-quality decision making.

Data → Information → Intelligence → Insight → Decision

3. Where are we now?

3.1. National ambitions

The National Palliative and End of Life Care Partnership is a group of national organisations with experience of, and responsibility for, end of life care. They set out six national ambitions which formed a framework for local action to improve palliative and end of life care between 2015 and 2020.

- Each person is seen as an individual
- Each person gets fair access to care
- Maximising comfort and wellbeing
- Care is coordinated
- All staff are prepared to care
- Each community is prepared to help

These are unchallengeable in their intent and were signed up to by the H&WB as part of the refreshed strategy in December 2018. The next step is to make them a reality across Sheffield.

3.2. Good work in single organisations

Exemplary care can be found across Sheffield in health and social care, the voluntary sector and in private homes. Examples include the receipt of the Royal College of Nursing Emergency Nursing Award for 2019, by STHFT's Emergency Department End of Life Team and the success of St Luke's EnComPaSS project in which new technology based models of care were used by the community palliative care service resulting in over 800 fewer A&E admissions and 8,700 hospital bed days for end of life patients in Sheffield.

Improving care at the end of life is the subject of internal improvement plans in many Sheffield organisations which can only be a good thing. However, if we are to optimise the end of life experience for all of Sheffield's citizens care must be taken to ensure those organisations' plans are fully aligned to an integrated direction of travel across the city.

3.3. Integrated Care System (ICS) support

Within the South Yorkshire and Bassetlaw (SY&B) ICS the importance of improving care at the end of life in a consistent and cost-effective way that also prepares for the anticipated demographic increase in end of life need is recognised. The need to understand and address place based and regional variations, develop shared standards and best practice, and leverage shared resources has been acknowledged in a commitment to end of life care for citizens of all ages, dying from all causes in SY&B.

It is recognised that the solution lies not in a single, region-wide delivery plan, service or mandate, but in the synergistic development and implementation of place based end of life strategies. This recognises the strength of supporting development at place level against agreed ICS and national standards and sharing resources where appropriate. The aspiration to share best practice includes approaches to shared records and intelligence in which Sheffield is recognised to be a regional and potential, national leader.

3.4. Accountable Care Partnership (ACP) End of Life strategic group

Built out of recognition that we need to work in partnership to deliver better integrated care services for people at the end of their lives, this group brought together Sheffield Clinical Commissioning Group (SCCG), St. Luke's Hospice and Sheffield Teaching Hospitals NHS Foundation Trust (STHFT). Some good foundations have been laid, and four local priorities identified:

- Commitment to deliver high-quality end of life care to anyone affected by terminal illness in Sheffield in the last few months of life.
- Commitment to deliver high quality services which are continually monitored to improve care to enable as comfortable, dignified and individualised an experience as possible.
- Promotion of better end of life care through the culture that care of the dying is everyone's responsibility.
- Providing the skills and tools to enable staff to deliver high quality end of life care.

However, driven by experience rather than intelligence, its aims are neither broad nor ambitious enough to deliver the transformational change needed in Sheffield.

3.5. Data and analytics

Very significant added value is available from being able to link data from different organisations' care records to aid our understanding of personal, social and care needs as the end of life approaches. Arrangements are already in place to do this and we are on the cusp of completing the exercise. In this arrangement data from the care records of individual patients from all the statutory

organisations in the city involved in providing care at the end of life are being collated centrally (at SCCG) in such a way that the records can be linked, anonymously, in any combination. This comprises care record data from STHFT, St Luke's, primary care and social care. It will enable a level of analytical sophistication and detail that has not previously been available and indeed, not achieved elsewhere. This, of course, will be limited to a degree by the extent and quality of information available from care records; so some important questions, for example concerning the 'experience' of dying, would necessitate the collection of additional data not presently recorded.

Due to information governance and legal considerations, there are some constraints on how and the extent to which individual organisations can contribute to the analytical effort; some organisations may be restricted to handling only aggregate data rather than at the level of the individual. However, the data sharing permissions we have in place include the two Sheffield universities, so a collaborative approach across partners offers some unprecedented possibilities in this sphere.

3.6. Transformational change

In summary, Sheffield has the all the necessary components to bring about the transformational change that the people of Sheffield deserve. This is recognised by national leaders who have great expectations that Sheffield is able to lead the way in this important area. However, these components are not yet fully aligned and working to one, single, strategic agenda for the city.

4. Where do we want to get?

The change we need to see is about more than organisations working better together, it will require cultural change in both professionals and the citizens of Sheffield where success will drive greater ambition via the knock-on effect of 'normalising' the experience of approaching the end of life with greater confidence in homes and communities across the city.

Such ambitions cannot be realised overnight. Indeed it is hard to define exactly how long, a 'long-term' vision may take to realise. It is thus important that short and medium term aims are described in order that the immediate needs of people and organisations don't get overlooked.

4.1. Short term

Many people currently experience the best support Sheffield can offer at the end of life and experience what would be described as a good death, but that is not guaranteed across the board. Evidence suggest that non-cancer patients, ethnic minority community groups, older people and marginal groups (i.e. homeless populations) have less access to specialist palliative care services[3]. A short term priority must be to deliver access to good quality care equitably across Sheffield.

4.2. Medium term

Better integration of services and improvement of community care should go some way towards closing the triple gap described in 2.2.1 but medium term aims need to be met in a way consistent with longer term ones.

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[3] Abel J, Kellehear A, Karapliagou A. Palliative Care – The New Essentials. Annals of Palliative Medicine 2018.

4.3. Long term

When we consider the multi-faceted nature of experience at the end of life, our long term ambition should be to go beyond focusing primarily on clinical care of terminal conditions (an approach that can lead to a reductionist focus on goals achievable within healthcare organisations) to a whole-city approach, aiming to meet people's needs holistically by bringing together effective elements within communities, civic institutions and clinical services.

This holistic approach to the end of life also enables the development of a model of practice that has the potential to support not only citizens affected by predictable terminal conditions (including extreme old age), but support more broadly, those affected by bereavement and sudden unpredictable death including deaths in maternity and children of all ages as well as transition.

Figure 1:
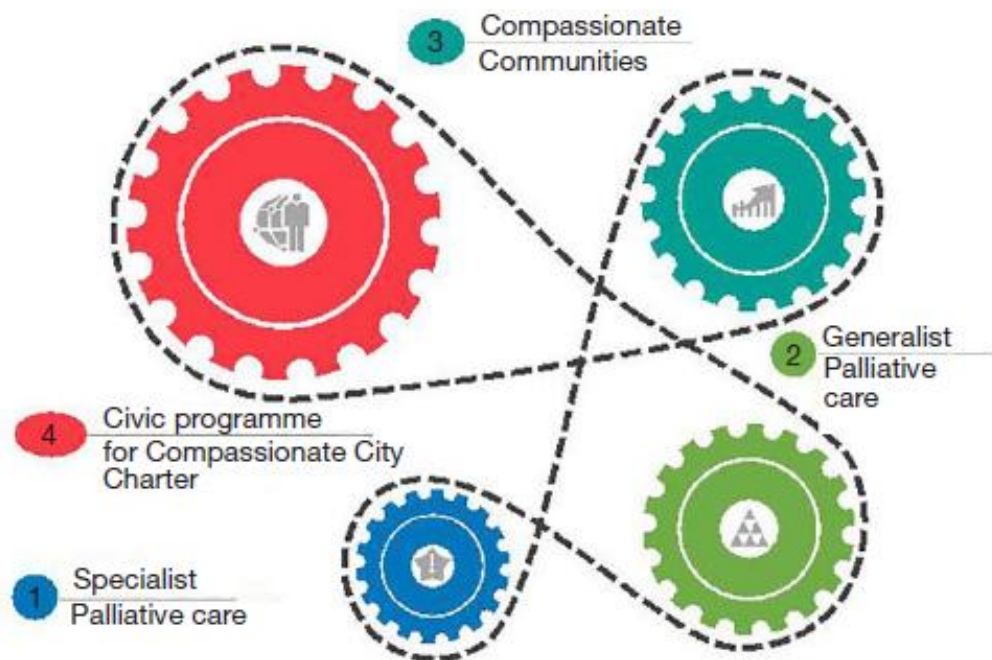
The model above represents an ambitious but achievable approach to supporting all people affected at the end of a life. The key to fulfilling the opportunities derived from this model are the integration of the processes and operations of its four components: Generalist Palliative Care, Specialist Palliative Care, Compassionate Communities and a civic approach to the end of life.

Compassionate Communities are naturally occurring networks of support in neighbourhoods and communities, surrounding those experiencing death, dying, caregiving, loss and bereavement.

The civic component of end-of-life care recognizes civic participation and co-operation from public sectors and institutions, as the basis upon which community care is based, and mobilises actions that support end-of-life care in public institutions. An example of a Charter of Actions for a Compassionate City is included at appendix 1.

10

Specialist and Generalist Palliative Care components of the model already form a recognised and valued part of end of life care delivery in Sheffield. However, the complexity of need and Generalist Palliative Care makes it difficult to describe absolutely the overlap between the two, and organise into concrete pathways and therapeutic practices. Given that access to Specialist Palliative Care is determined by referral from generalist services, these complexities potentially lead to inequity of access, which at present is hard to characterise and almost impossible to quantify. There needs to be a continuum of support between specialist, generalist, community and civic end-of-life care, so that support is offered at the most appropriate level and according to need.

There are many challenges in effectively implementing such a model: knowing to what extent the component parts play a role in supporting a good end of life experience in different contexts and understanding the impact, fairness and cost-effectiveness as we implement new practices form just a few. All however, illustrate the importance of system change being underpinned and driven by an ongoing, dynamic use of best available intelligence.

5. How do we get there?
5.1. Intelligence
We need to develop an intelligence (data) led approach to our work. This is because we need to be able to better understand and predict future end of life health and care needs, reduce health inequalities associated with the end of life and make better use of the resources available to us.

There are a number of datasets and data sources available to us in the city to support this work but they currently operate within individual organisational silos. We therefore need to be able to link these various data sets together. Linked data allows us to generate new insights at a system and population level. This facilitates development of interventions tailored to specific cohorts of people and specific types of outcomes. The key impacts of linked data are:

- Improved population level data about needs to drive planning and delivery of proactive care to achieve maximum impact.
- Segmentation and stratification modelling to identify local 'at risk' cohorts and to quantify effectiveness and cost effectiveness.
- Targeted interventions that improve outcomes for people and their families and reduce unwarranted variations in outcomes.

The IG and IT infrastructure and arrangements and appropriate workforce expertise exist locally to enable us to do this. Specifically though, with the support and endorsement of the H&WB, data sharing arrangements need to be maintained by relevant partners who also need to deploy elements of their IT and workforce to support this work.

5.2. Partnership
System-wide solutions are required, driven by population, rather than individual organisational, need. Thus it is imperative that we work in partnership to ensure our endeavours complement each

11

other, avoid duplication of our efforts and that our citizens experience seamless support to meet their physical, psychological, spiritual and social needs.

5.3. Whole city

Delivering this model would require engagement of partners well beyond the Health and Wellbeing Board including for example, workplaces, faith groups, recreational groups and the local media.

6. Questions for the board

- Does the Health and Wellbeing Board accept that a comprehensive end of life approach, including community and civic elements is most likely to deliver best outcomes for Sheffield? If so, would the Board sponsor a workshop to consider whether Sheffield should become a 'Compassionate City' and how best to progress that?

- How will the Board help to engage and enable leaders from within communities and neighbourhoods?

- Can Board members give their individual organisational commitment to an integrated intelligence function to deliver this work?

- Does the Board support further development of a strategy based on the six national ambitions with the addition of a dynamic intelligence core?

THE COMPASSIONATE CITY [4]
- A CHARTER of ACTIONS -

Compassionate Cities are communities that recognize that all natural cycles of sickness and health, birth and death, and love and loss occur everyday within the orbits of its institutions and regular activities. A compassionate city is a community that recognizes that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility.

Compassionate Cities are communities that publicly encourage, facilitate, supports and celebrates care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care. Though local government strives to maintain and strengthen quality services for the most fragile and vulnerable in our midst, those persons are not the limits of our experience of fragility and vulnerability. Serious personal crises of illness, dying, death and loss may visit any us, at any time during the normal course our lives. A compassionate city is a community that squarely recognizes and addresses this social fact.

Through auspices of the Mayor's office a compassionate city will - by public marketing and advertising, by use of the cities network and influences, by dint of collaboration and co-operation, in partnership with social media and its own offices – develop and support the following 12 social changes to the cities key institutions and activities.

- Our schools will have annually reviewed policies or guidance documents for dying, death, loss and care

- Our workplaces will have annually reviewed policies or guidance documents for dying, death, loss and care

- Our trade unions will have annually reviewed policies or guidance documents for dying, death, loss and care

- Our churches and temples will have at least one dedicated group for end of life care support

- Our city's hospices and nursing homes will have a community development program involving local area citizens in end of life care activities and programs

- Our city's major museums and art galleries will hold annual exhibitions on the experiences of ageing, dying, death, loss or care

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[4] From K.Wegleitner, K Heimerl, A. Kellehear (2016) Compassionate Communities: Case studies from Britain and Europe. Abingdon, Routledge, 2016, pp 80-82

- Our city will host an annual peacetime memorial parade representing the major sectors of human loss outside military campaigns – cancer, motor neuron disease, AIDS, child loss, suicide survivors, animal companion loss, widowhood, industrial and vehicle accidents, the loss of emergency workers and all end of life care personnel, etc.

- Our city will create an incentives scheme to celebrate and highlight the most creative compassionate organization, event, and individual/s. The scheme will take the form of an annual award administered by a committee drawn from the end of life care sector. A 'Mayors Prize' will recognize individual/s for that year those who most exemplify the city's values of compassionate care.

- Our city will publicly showcase, in print and in social media, our local government policies, services, funding opportunities, partnerships, and public events that address 'our compassionate concerns' with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long term caring. All end of life care-related services within the city limits will be encouraged to distribute this material or these web links including veterinarians and funeral organizations

- Our city will work with local social or print media to encourage an annual city-wide short story or art competition that helps raise awareness of ageing, dying, death, loss, or caring.

- All our compassionate policies and services, and in the policies and practices of our official compassionate partners and alliances, will demonstrate an understanding of how diversity shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.

- We will seek to encourage and to invite evidence that institutions for the homeless and the imprisoned have support plans in place for end of life care and loss and bereavement.

- Our city will establish and review these targets and goals in the first two years and thereafter will add one more sector annually to our action plans for a compassionate city – e.g. hospitals, further & higher education, charities, community & voluntary organizations, police & emergency services, and so on.

This charter represents a commitment by the city to embrace a view of health and wellbeing that embraces social empathy, reminding its inhabitants and all who would view us from beyond its borders that 'compassion' means to embrace mutual sharing. A city is not merely a place to work and access services but equally a place to enjoy support in the safety and protection of each other's company, even to the end of our days.