Scrutiny

Leicester City Council

Scrutiny Review

End of Life Care

DRAFT

A Review Report of the Adult Social Care Scrutiny Commission

October 2018

Leicester City Council

Contents

Page

Chair's Foreword **1**
1 Executive Summary **2**
2. Recommendations **3**
3. Report **3**
3.1. What is End of Life Care? 3
3.2. What does good End of Life Care look like? 4
3.3. Specific Available Services for EOL 4
3.4. Position in Leicester 5
3.5. Experience of EOL in Leicester 7
4. Financial, Legal and Other Implications **9**
4.1. Financial Implications 9
4.2. Legal Implications 9
4.3. Climate Change Implications 9
4.4. Equality Implications 9
5. Officers to Contact **9**

DRAFT

Chair's Foreword

End of Life Care for our loved ones is one of the most difficult and sensitive situations we must cope with. Most of us face this usually with our parents and/or grandparents and wish for a quiet, peaceful death in our own home when the time comes.

The way in which care is provided is a very important part of the complex picture that makes up the pathway to the end of life. It can involve medical and health interventions as well as adult social care (ASC).

Within the adult social care environment, End of Life is a small part of the service provision within the city. In Leicester, there is a growing pattern of chronic ill-health, often supported over months or years by ASC personnel, leading to hospitalisation as health starts to fail and finally release from hospital to allow death at home (in a domestic home, residential care or nursing home).

This review looked at how the ASC department and associated teams addressed the issue and how they and other care providers work together and with health providers and carers who are often the first line of support for frail and elderly people.

We are heartened by the levels of co-operation and support by services, care providers and individual carers across the city. We found very good examples of supportive care.

Our conclusions are overwhelmingly supportive of the department which faces a history and future of underfunding created by successive financial cuts by government. Despite the pressures, the department delivers not just a good End of Life Care service but services across a range of demands for the citizens of Leicester.

Councillor Virginia Cleaver

Task Group Chair and Vice Chair, Adult Social Care Scrutiny Commission 2017/18

DRAFT

1 Executive Summary

1.1. Background to the Review

1.1.1. Each year, around 500,000 people die in England and they are set to rise by approximately 16.5% by 2030 which equates to some 90,000 additional deaths each year (590,000).

1.1.2. Clearly the supply of hospital and hospice beds will not keep pace with that rate even if that were the appropriate response. So, a big question to consider is ‘will residential/nursing home or community care services be equipped?’.

1.1.3. By 2030 those aged over 65 will account for 86.7% of all deaths with those over 85 accounting for 43.5% (a marked increase from 32% in 2004). A significant proportion will have multiple conditions with approximately 29% also having dementia. Around 70% of people express a wish to die at home. This means that by 2030 we need either 20% more institutional beds or we need to develop new ways to meet people’s needs, for example community based models and End of Life Care training for all, so that needs can be met as part of everyone’s practice. At the same time informal carers will also be becoming older with possibly multiple conditions which may well affect their ability to fulfil their carer role.

1.1.4. The ability of Leicester to respond to this growth in need will be critical. The commission can’t emphasise enough the importance of being able to react to this, and allowing people to come to a dignified end when they have already experienced so much. As such, we have decided to do this review to look at End of Life Care and what the current position is and how it is done.

1.1.5. The review solely looked at adult social care aspects of end of life (EOL) but recognised that the vast amount of work in this area is done by NHS services. The review offered much food for thought and offers a quick snapshot into an area which undoubtedly needs exploring further as something which needs to be made much more of a priority for all people to ensure those at the end of life are able to depart with dignity, comfort and love.

DRAFT

2. Recommendations

The Assistant Mayor for Adult Social Care and the Executive are asked to consider the following recommendations:

2.1. Assurances are sought that social care practitioners dealing with people at the end of life are skilled in having conversations about end of life with either the person involved and/or their family from an early stage.

2.2. Assurances are sought that the different needs, which should include cultural backgrounds and other demographic information for the individual, are considered when talking to patients and families about End of Life pathways in the social care setting.

2.3. The ICRS team protocols are reviewed to ensure their out of hours procedures are well equipped to deal with end of life.

The Health and Wellbeing Scrutiny Commission are asked to consider the following recommendations:

2.4. Consider looking at how the Derby and Derbyshire Out of Hours End of Life care service operates with the ASC Department and NHS Services. Where possible best practice from this model should be embedded in Leicester, Leicestershire and Rutland End of Life protocols.

2.5. Consider looking into End of Life Care by NHS services and ensure that early conversations are being had with patients and their families.

3. Report

3.1. What is End of Life Care?

3.1.1. There is often confusion between End of Life and Palliative Care, but the two are clearly distinct. Palliative Care is for people living with a terminal illness where a cure is no longer possible. It's not just for people diagnosed with terminal cancer, but any terminal condition or those who have a complex illness and need their symptoms controlled.

3.1.2. The aim of Palliative Care is to treat or manage pain and other physical symptoms as well as help with any psychological, social or spiritual needs. This may include treatment such as medicines, therapies, and any other support that specialist teams believe will help their patients. It includes caring for people who are nearing the end of life.

3.1.3. End of Life Care is an important part of Palliative Care for people who are nearing the end of life. This is for people who are considered to be in the last year of life, although this timeframe can be difficult to predict. End of Life Care aims to help people live as well as possible and to die with dignity. It may include treatment during this time and can include additional

DRAFT

support, such as help with legal matters. End of Life Care continues for as long as is needed to ensure a peaceful end for the person and their family.

3.1.4. Ensuring the medical management and emotional support is in place at the right time in the right place for the right people in End of Life Care is an important service provided by social care and health services to ensure that people can end their lives in a comfortable manner with dignity, taking into account their wishes. Consideration for carers and family support is also a paramount importance in End of Life (EOL).

3.1.5. With all this in mind the commission felt it was important to consider how we perform in the city and how well our social care service contributes to the overall needs of dying people within the wider health and care system.

3.2. What does good End of Life Care look like?

3.2.1. Before being able to assess if we provide good social care at EOL, it was important for the commission to understand what good End of Life Care looked like.

3.2.2. The commission heard that this was specified in the document by the Association of Palliative Social Care Workers; 'The Role of Social Workers in Palliative, End of Life and Bereavement Care 2016 (http://www.apcsw.org.uk/resources/social-work-role-eol.pdf).

3.2.3. This document contained a checklist of what social workers should offer at the End of Life and what the social workers' capabilities should entail when offering End of Life or Palliative Care.

3.2.4. The commission was assured that this is what the social care teams worked to and was the guidance that was followed.

3.2.5. It was extremely apparent though that much of EOL care is provided by Health Services and that this is something that may need to be explored by Health Scrutiny in the future to ensure that the best care in those settings is being offered at EOL.

3.3. Specific Available Services for EOL

3.3.1. Adult End of Life Care in Leicester is provided by a community health service provider, an acute hospital (across 3 sites), 62 GP practices, one out of hours provider, one walk in centre, one urgent care centre, one mental health trust, Leicester City Council adult social care services, East Midlands Ambulance Service and the voluntary and independent sectors, including one adult hospice.

3.3.2. The main community Palliative Care services are offered by LOROS, Hospice at Home (delivered by Marie Curie) and the Leicestershire Partnership Trust Macmillan Nurses.

DRAFT

3.3.3. Leicester City Clinical Commissioning Group aims for the EOL Care Service to:

- Improve the quality of End of Life Care;
- Support care in the patient's place of preference;
- Prevent unnecessary or inappropriate admissions for people at End of Life.

3.3.4. In terms of Adult Social Care, it was heard that Integrated Crisis Response Service (ICRS) looked at the situations of people who needed care inside two hours. This includes risk assessments and discharge cases; team members looked at End of Life and picked up urgent cases and provided support for them and their families. Based at the Neville Centre on the Leicester General Hospital site, ICRS is part of a wrap-round service. Funded through the Better Care Fund (BCF) the service often has closer links with patients at EOL than other services.

3.4. Position in Leicester

3.4.1. Leicester Joint Strategic Needs Assessment (JSNA): End of Life Care (2016) states that most deaths occur in people aged over 65 (85%). In Leicester City, there are around 2,500 deaths per year, approximately 0.8% of the population total. Nationally, 25% of all deaths are unexpected, for Leicester, this is the equivalent of 625 deaths.

3.4.2. The JSNA also adds that cancers, circulatory disease and respiratory conditions account for 70% of deaths that are not sudden. The Palliative Care Funding Review report indicates that between 69% and 82% of deaths are likely to have Palliative Care needs; this means that between 1,725 - 2,050 people who die in Leicester every year will require Palliative Care.

3.4.3. In Leicester, for the year 2014/15, 2478 after death audits were completed for patients registered with Leicester GPs. Of these, 2,189 (88.3%) of people with a care plan died in their preferred place of choice.

3.4.4. The Quality and Outcomes Framework Palliative Care Register has 1,827 patients registered for 2014/15, of which 1,272 (70%) had care plans. On 1st July 2015, 1,834 patients were recorded on the Palliative Care Register for Leicester City. Over 75% of the patients on the register had developed an End of Life care plan with their GP or healthcare professional.

3.4.5. The JSNA said that in Leicester in 2014/15, 2,659 people over 18 and registered with Leicester GPs died. 2,478 after-death audits were completed and it was evaluated that 2,189 (88.3%) people with a care plan died at their preferred choice. In 2014/15 in Leicester, the Qualities and Outcomes Framework Palliative Care Register had 1,827 patients recorded; of which 1,272 (70%) had care plans.

DRAFT

3.4.6. The table below shows the percentage of deaths by place of death: 2011-2013

		Hospital	Home	Care Home	Hospice	Other
Persons all ages	Leicester deaths	1173	571	455	112	69
	Leicester %	49.3	24.0	19.1	4.7	2.9
	England %	49.3	22.2	20.7	5.7	2.1
Persons <65	Leicester deaths	238	155	13	40	31
	Leicester %	50	32.4	2.7	8.5	6.5
	England %	47	32.9	2.7	10.6	6.8
Persons 65-84	Leicester deaths	553	280	160	57	22
	Leicester %	51.6	26.1	15.0	5.3	2.1
	England %	52.2	24.9	14.3	7.1	1.5
Persons 85+	Leicester deaths	381	137	282	15	16
	Leicester %	45.9	16.5	33.9	1.8	1.9
	England %	46.8	14.5	35.7	1.9	1.0
Males, All ages	Leicester deaths	612	321	170	58	41
	Leicester %	50.9	26.7	14.1	4.8	3.4
	England %	51.2	25.6	14.4	6.0	2.8
Males, < 65	Leicester deaths	144	103	9	21	24
	Leicester %	47.9	34.2	3.0	6.9	8.0
	England %	45.5	35.0	2.5	8.2	8.8
Males 65-84	Leicester deaths	300	154	73	28	13
	Leicester %	52.9	27.1	12.8	5.0	2.2
	England %	52.7	26.8	11.9	7.0	1.6
Males 85+	Leicester deaths	168	64	88	9	5
	Leicester %	50.2	19.2	26.5	2.7	1.4
	England %	52.3	17.2	27.0	-	0.9
Females all ages	Leicester deaths	561	251	285	54	28
	Leicester %	47.6	21.3	24.2	4.6	2.3
	England %	47.6	18.9	26.6	5.4	1.5
Females <65	Leicester deaths	95	52	4	20	7
	Leicester %	53.5	29.4	2.1	11.1	4.0
	England %	49.4	29.8	3.0	14.1	3.7
Females 65-84	Leicester deaths	253	126	88	29	9
	Leicester %	50.2	24.9	17.4	5.7	1.9
	England %	51.6	22.7	17.1	7.3	1.4
Females 85+	Leicester deaths	214	73	194	6	11
	Leicester %	43.0	14.7	38.9	1.1	2.3
	England %	43.7	13.0	40.7	1.5	1.0

DRAFT

3.5. Experience of EOL in Leicester

3.5.1. Evidence from Leicester Ageing Together (LAT) heard that End of Life has appeared as an issue for them as an organisation and they were about to provide End of Life preventative services, building assets among lonely over-50s and developing a befriending service. Some of their volunteers are coming across people who are either old and facing death or who have an illness known to be terminal.

3.5.2. LAT stated that they are beginning to have the conversations slipped into the everyday with their clients about EOL. Many of their clients live alone and are over 80 but their family often doesn't want to talk about it. The aim for them is to allow people to take charge of their own death where possible. Commission members suggested that it was important that people and practitioners dealing with people at End of Life are upskilled to have those difficult conversations and that it is not just about a checklist approach, but that a conversation needs to be had with both the patient and family members.

3.5.3. **Recommendation: Assurances are sought that social care practitioners dealing with people at End of Life are skilled in having conversations about End of Life with either the person involved and/or their family from an early stage.**

3.5.4. Aspire UK also stated that they work with people with complex needs in their own home. Via the End of Life Forum, they have been supported to work with medical specialists and family and have links to Palliative Care and learning disabilities charities.

3.5.5. They stated that people that might have otherwise died (e.g. with Down's Syndrome) have survived through improved medication. They also said that clients sometimes did not wish to take a decision about their End of Life pathway but would prefer to get a relative (or indeed anyone else) to decide for them. They also stated that they don't label people and take into consideration the very different cultural and community backgrounds found within Leicester when arranging and managing End of Life Care. This was another point that commission members felt was important as different cultural backgrounds have different needs and approaches that must be considered when talking about EOL.

3.5.6. **Recommendation: Assurances are sought that the different needs, which should include cultural backgrounds and other demographic information for the individual, are considered when talking to patients and families about EOL pathways in the social care setting.**

3.5.7. Evidence from Ideal Care Homes suggested that the out of hours service in the city was 'patchy' in comparison to that provided in Derbyshire. The way in which GPs delivered a gold standard, the District Nurse directive and how it was implemented, was not always done in Leicester and some learning could be had from Derbyshire.

DRAFT

3.5.8. Aspire also felt that while GPs were supposed to visit people on End of Life plans, in their experience no meetings had been held for two years with service users they came across. It was suggested to the Task Group that it was possible in some cases End of Life programmes were being introduced too quickly; that people were being written off too soon. There was a suggestion that maybe there needed to be an interim stage of care, perhaps an advanced care plan.

3.5.9. **Recommendation: The ICRS team protocols are reviewed to ensure their out of hours procedures are well equipped to deal with EOL.**

3.5.10. **Recommendation: The Health and Wellbeing Scrutiny Commission considers looking at the how the Derby and Derbyshire Out of Hours End of Life care service operates with the ASC Department and NHS Services. Where possible best practice from this model should be embedded in Leicester, Leicestershire and Rutland EOL protocols.**

3.5.11. The commission heard repeatedly that EOL was predominantly a primary care issue and was very much needing to be led by NHS colleagues. With other factors such as Delayed Transfers of Care (DTOCs) taking precedent, EOL often finds itself lower on the priority list.

3.5.12. The commission are clear that earlier conversations about EOL options need to take place, and with as many people as possible. Individuals and their families overwhelmingly refused to discuss EOL options until it was far too late and this needed to be a much higher priority for practitioners in order to ensure people came to a dignified end, with their wishes catered for.

3.5.13. Evidence heard suggested that cancer patients are maybe more aware of options at the EOL than other patients, with good work done by LOROS and Macmillan and the practitioners working with them to discuss options. The commission felt this needed to be replicated across all patients regardless of the illness.

3.5.14. At the point people go into care, the discussion about EOL should be had and the relevant forms completed, information gathered, considering the sensitivity of whether the service user wants to discuss it, the extent to which they might be willing to take the discussion and this personal profile should be reflected in the documentation. Ideally, this conversation would also involve family support. It should reflect and document clearly the cultural and religious framework for the service user’s End of Life Care and support. If the service user is not willing to discuss EOL arrangements, they should be asked if close family members’ views may be sought at another time.

3.5.15. **Recommendation: The Health and Wellbeing Scrutiny Commission consider looking into EOL care by NHS services and ensure that early conversations are being had with patients and their families.**

DRAFT

4. Financial, Legal and Other Implications

4.1. Financial Implications

There are no direct financial implications.

Yogesh Patel – Accountant, Ext 4011

4.2. Legal Implications

There are no direct legal implications.

Jenis Taylor – Principle Solicitor (Commercial), Ext 1405

4.3. Climate Change Implications

There are no significant climate change implications associated with this report.

Aidan Davis – Sustainability Officer, Ext 2284

4.4. Equality Implications

Under the Equality Act 2010, public authorities have a Public Sector Equality Duty (PSED) which means that, in carrying out their functions, they have a duty to pay due regard to the need to eliminate unlawful discrimination, harassment and victimisation, to advance equality of opportunity between people who share a protected characteristic and those who don't and to foster good relations between people who share a protected characteristic and those who don't.

Protected Characteristics under the Equality Act 2010 are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation.

The report recommendations with regards to End of Life care need to be considered as part of any ongoing work in this area and the relevant protected characteristics need to be taken into account.

It is important that Health and social care commissioners and providers work closely with local communities to make sure they understand their needs and develop care that is sensitive and responsive to them and that all communities understand the choices available to them; that people, carers, families and professionals are empowered to have the right

DRAFT

conversations about death and dying; and people from all communities are treated with dignity and respect.

If the ICRS team protocols are reviewed to ensure their out of hours procedures are well equipped to deal with EOL, it is advised that an Equality Impact assessment is carried out to ensure that equalities implications of any proposed changes are fully analysed and that the Council can demonstrate 'due regard' for the aims of the Public-Sector Equality Duty.

Learning from best practice and the experiences, expectations and needs of people from across all protected characteristics are a vital component of how we will deal with an ageing population and the approach to death and dying as a society.

Surinder Singh – Equalities Officer, Ext. 4148

5. Officers to Contact

Megan Arianna Law
Scrutiny Policy Officer
Tel: 0116 454 0464
Email: Megan.Law@leicester.gov.uk

DRAFT