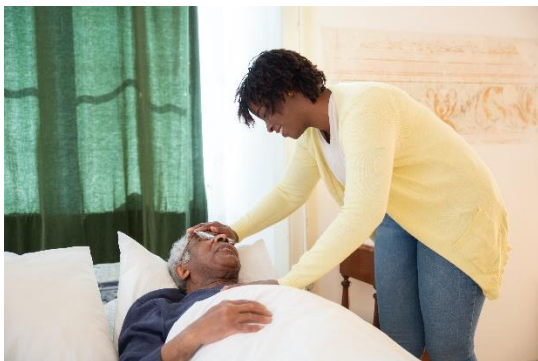


# Community Asset Mapping: Die Well – End of Life Care

August 2022



# North East Essex Health and Wellbeing Alliance Community Assets Mapping



## Die Well – End of Life Care August 2022

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## Introduction

The Die Well Deep Dive is the third in a series of reports published as companions to the Community Assets Mapping refresh of North East Essex, originally published in Spring 2021. Using the North East Essex Health and Wellbeing Alliance domains as a framework for each report, there will ultimately be a library of six reports:

- Start Well - completed over the Summer of 2021
- Feel Well - conducted during Autumn 2021
- Be Well
- Age Well
- Stay Well - beginning Summer 2022
- Die Well - conducted during Spring 2022

The report has been produced by Healthwatch Essex, CVS Tendring and Community360, working in partnership, and collaborating with a Steering Group, which has included the Die Well domain lead, representatives from District and County Councils, Essex Fire and Rescue, the Local Delivery Pilot, North East Essex Clinical Commissioning Group, ESNEFT and Age Well East.

## Scope and Methodology

In learning from the completion of the first two deep dive reports for Start Well and Feel Well, this document is a continued refinement of a process and evolves as the asset mapping programme delves into new topics. Of primary concern was maintaining an Asset Based Community Development (ABCD) approach in a local context. This involved grounding research in local knowledge whilst using national and regional data sets, where available, for cross reference.

A clear outline for the report was shaped through consultation with the Steering Group and Die Well domain and involved topic specific specialists and relevant organisations.

It was agreed that the work would consider key drivers and influences on people determined to be at or near end of life and would use learning from the last 12-18 months. It would gather information through a literature search and primary research which accurately reflects:

- A deeper understanding of what facilitates and what presents barriers to access to services and how to address them
- Key strengths and challenges for people and their family/carers at end of life within the community
- Local cultural factors and limitations
- End of life care in residential and nursing homes and support to live at home

It was agreed to focus the citizen's voice work in the Tendring wards of Lawford, Manningtree and Mistle and Shrub End and Prettygate wards in Colchester. These are areas with broad demographics within the population, that would enable access to carers and people with experiences of end of life care.

The work focused on:

- National vs local assets - pathways to self-access, how are they promoted?
- Compassionate Communities - making the community input count to deliver positive outcomes for people and their family/carers at end of life
- Networks of care
- Cultural diversity - learning from different ways of practice; overcoming language and understanding barriers

This report is collated from engagement with organisations and individuals across North East Essex. The primary focus is on people in their last 12 months of life and their family and informal carers. It should be seen in context of the Die Well overall aim which is “*to optimise the prioritised outcomes for adults in the last year of life in North East Essex and to address inequalities*”. The overall outcome being that “*all individuals nearing end of life have choice around their care*”.

This would be evidenced by:

1. People who are identified in the last 12 months of life
2. People thought to be within the last 12 months of life and their families are informed of the likelihood of death within the next 12 months sensitively and honestly
3. People’s preferences for care are elicited and recorded during the last 12 months of life
4. People’s preferences for care are respected during the last 12 months of their life
5. People’s preferences for care are accessible to all parts of the health and social care system/end of life care system
6. People at end of life are treated as individuals, with dignity, compassion and empathy
7. People’s pain and symptoms are managed and controlled during the last 12 months of life
8. We are able to minimise inappropriate, unnecessary and futile medical intervention during the last 12 months of people’s life
9. People at end of life have equitable access to flexible 24/7 end of life care services irrespective of the place of care or the organisation/s providing care
10. Families and carers are provided support during and after their loved one’s end of life

We would like to thank everyone who has contributed towards this report formally or informally, and hope that the content offers further insight into the experiences of local people and organisations working in the voluntary and community sector. Data gathering and consultation was conducted between February 2022 and June 2022.

## **Acknowledgements**

Healthwatch Essex, Community360 and CVS Tendring would like to thank the organisations and residents who participated in all sections of the report, and notably as citizen's voices. Their experiences and data help to improve the understanding of this area of work.

## Context

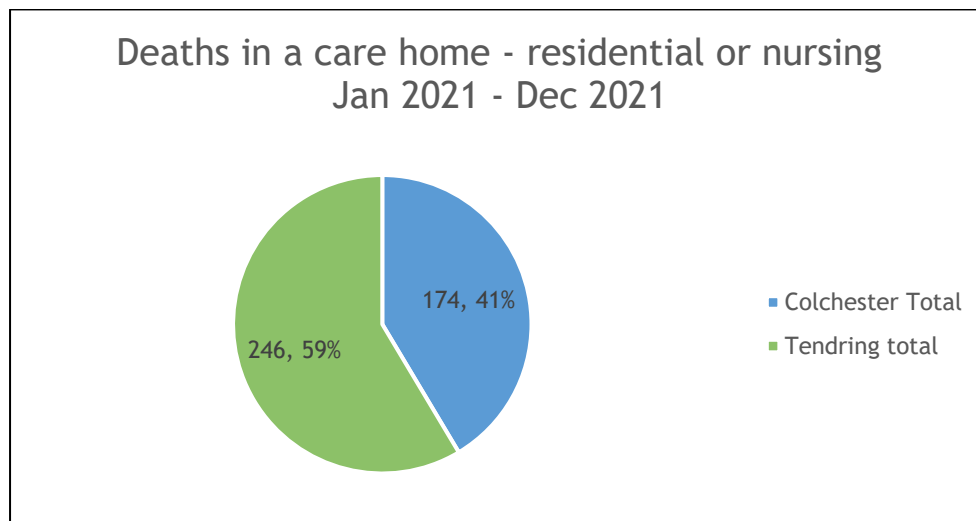
Extensive work has been undertaken with the Die Well domain and under the guidance of the End of Life Board to establish the context of care in North East Essex.

Through working with members of the Board, St Helena and colleagues within the North East Essex Health and Wellbeing Alliance, gathering data for the Neighbourhoods programme, some key information emerges to accompany the report.

## Local data

Overleaf presents a table offering a breakdown of people by Primary Care Network (PCN) who are living with long term health conditions, access the My Care Choices Register (MCCR) and place of death and clinical support, such as anticipatory prescribing. Where PCN's cover Colchester and Tendring, the data has been split to reflect the local population in each district. This indicates where additional support may be helpful.

In addition, the chart below shows deaths in a care home. Residential/nursing care provide a home for many residents in Colchester and Tendring, being home for many years for some. This provides a huge opportunity to hold early discussions with residents and their families in order to complete a My Care Choices Record in a timely fashion and in full. The support of Social Prescribers have helped to improve the number of MCCRs on the register.



End of life data comparisons for the last 12 months (2021-22) comparing trend with the previous 12 months (2020-21)

Colchester Primary Care Networks

	Registered population	Average Deprivation	% with long-standing health condition	% with long standing MH condition	% who died in last 12 m on MCCR vs all deaths	% achieving MCCR PPC	% who died in hospital	% people with anticipatory prescribing completed	% with 3+ emergency admissions in last 90 days
Colchester Medical Practice	38539	21.83	45.06	10.07	50.7	71.7	44.4	40.7	9.7
COLTE (ARA)	23428	13.8	57.33	12.83	63.6	75.6	35.3	44	10.1
COLTE (RMT)	35788	12.77	49.19	8.36	46	80.6	46.5	50	11.6
COLTE (WCW)	19722	12.36	50.42	7.31	41.8	79.4	41	59.6	10.6
Creffield	38686	16.09	51.18	10.09	56.7	88.7	36.4	53	12.9
East Hill & Abbeyfield	36809	20.29	56.09	14.06	56.9	85.8	34.4	38.9	15.7
Mill Road Group	34680	14.58	48.84	10.78	52.1	89.8	31.9	43.6	11.4
Tendring	10489	20.96	62.39	9.89	52.8	77.2	41.8	42.3	7.3

Tendring Primary Care Networks

	Registered population	Average Deprivation	% with long-standing health condition	% with long standing MH condition	% who died in last 12 m on MCCR vs all deaths	% achieving MCCR PPC	% who died in hospital	% people with anticipatory prescribing completed	% with 3+ emergency admissions in last 90 days
COLTE (ARA)	6516	14.19	54.47	3.93	63.6	75.6	35.3	44	10.1
COLTE (WCW)	8295	28.04	60.52	5.61	41.8	79.4	41	59.6	10.6
Mill Road Group	4151	15.01	42.43	1.12	52.1	89.8	31.9	43.6	11.4
Tendring	31506	34.04	59.62	15.05	52.8	77.2	41.8	42.3	7.3
PCN Clacton	44904	33.35	60.03	13.27	42.2	79.1	41.6	56.8	9.8
Ranworth PCN	32520	35.18	60.92	11.65	43.9	81.1	42.6	66.2	11.2



## Legend

	Worsening trend
	One to watch - within +or- 2%
	Improving trend

## Notes

Highest average deprivation is Ranworth PCN - however, it is important to note that there is deprivation and affluence in all PCN areas and deprivation is a key area to focus on.

Most long-term conditions are in the Colchester registered population of Tendring practice.

The End of Life dashboard figures (coloured according to trend) for practices covering Colchester and Tendring are amalgamated, it is not possible to determine the local disparities

## Literature Review

### Inequalities

In July 2016, the Department of Health published a report <sup>1</sup> intended to drive improvement in End of Life care and choices available to those at end of life. It stated:

*“Our commitment to you is that, as you approach the end of life, you should be given the opportunity and support to:*

- *Have honest discussions about your needs and preferences for your physical, mental and spiritual wellbeing, so that you can live well until you die*
- *Make informed choices about your care, supported by clear and accessible published information on quality and choice in end of life care; this includes listening to the voices of children and young people about their own needs in end of life care, and not just the voices of their carers, parents and families*
- *Develop and document a personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness*
- *Share your personalised care plan with your care professionals, enabling them to take account of your wishes and choices in the care and support they provide, and be able to provide feedback to improve care*
- *Involve, to the extent that you wish, your family, carers and those important to you in discussions about, and the delivery of, your care, and to give them the opportunity to provide feedback about your care*
- *Know who to contact if you need help and advice at any time, helping to ensure that your personalised care is delivered in a seamless way”*

Macmillan Cancer Support undertook some research in 2017 which demonstrated *“The fact that people are suffering in their precious final weeks is heart-breaking. But the real injustice - and we have a growing body of evidence for this - is that your experience when you die can depend on where you live and who you are.”* <sup>2</sup>

*“Something as fundamental as dying with your basic human needs met should not differ. It should be something we can all count on, for ourselves and the people we care about, regardless of who we are.”*

The report presents evidence that people from deprived areas were 18% more likely to die in hospital, rather than at home or in a hospice and that they were likely to have 20% more emergency admissions in their last weeks of life. Even now, in North-East Essex, people have described how distressing it can be for this to happen when peace, calm and pain-free is what is needed.

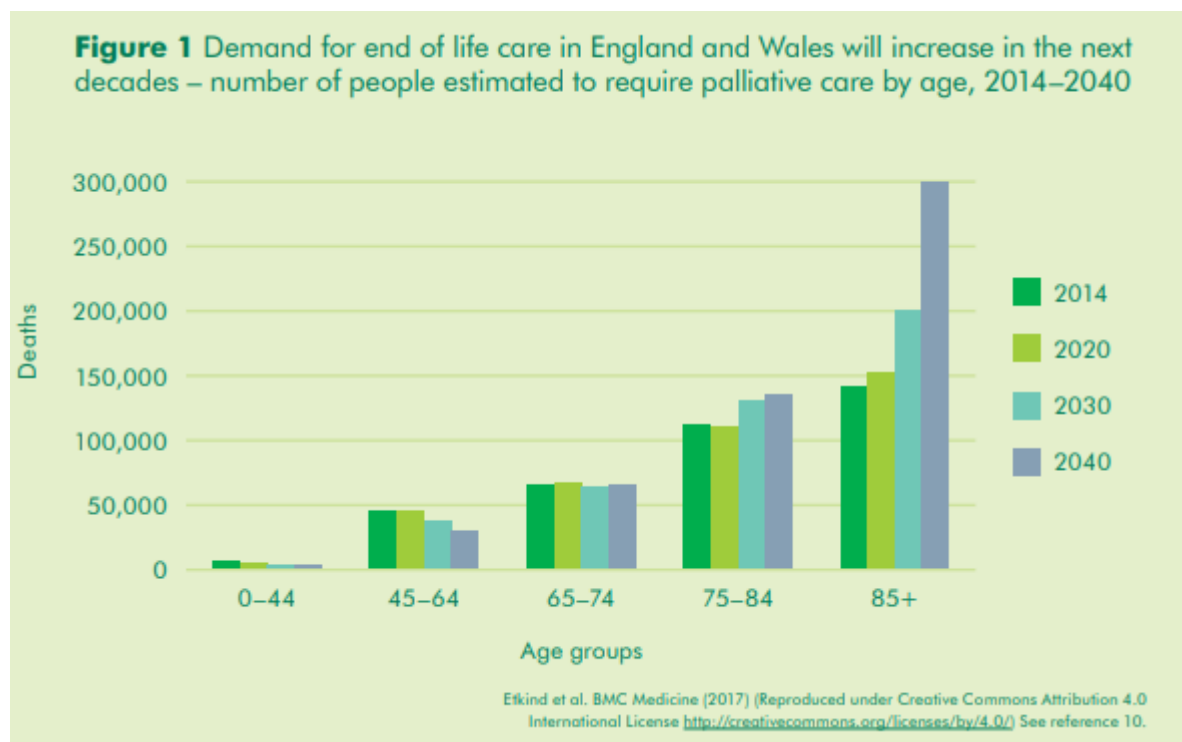
The Macmillan report states that in 2017, there were predicted to be around 490,000 deaths in England. Looking ahead to 2035/36, this figure is predicted to rise by nearly 20% to over 580,000 (source - ONS). As people live longer, often with much more complex medical conditions, the demand for end of life care will increase, as will the level of

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<sup>1</sup> ‘Our Commitment to you for end of life care: the Government Response to the Review of Choice in End of Life Care’, Department of Health, July 2016

<sup>2</sup> ‘The Final Injustice – variation in the end of life care. Macmillan Cancer Support, December 2017

support for individuals at end of life and their families/informal carers. The table below (taken from the report) illustrates this well.



The report cites various reasons why there may be inequality in the type of end of life care:

*‘This inequality reflects a lack of consistency in the support for dying people in the community, particularly the availability of coordinated out-of-hospital care for pain control and other forms of symptom management 24 hours a day, seven days a week. Other factors could also be affecting the most deprived people when they die, for example:*

- *Less appropriate housing for end of life care at home*
- *A greater reliance on emergency care over elective care*
- *Limited or overstretched social support*
- *Lower rates of health literacy, general literacy and education resulting in less choice and planning in end of life care*
- *Differences in lifestyle resulting in a higher rate of cancer types with poor survival rates, such as lung cancer*
- *Inability to bear the costs of caring for someone at home.’*

*Dr Pete Nightingale, Macmillan GP Advisor*

There is also potentially a lack of trust and confidence in end of life care at home, or difficulties accessing hospices due to transport costs or lack of transport availability. The multi-agency partnership of End of Life Care Board scrutinises End of Life care choices and provision through its performance dashboard and acknowledges that in North East Essex, there is still room for improvement but, despite the impact of Covid, positive improvements continue.

In May 2016, CQC published its report 'A Different Ending: Addressing inequalities in end of life care'. The research looked at the experiences of specific groups of people at end of life. These groups are:

- People with conditions other than cancer
- Older people
- People with dementia
- People from Black and minority ethnic groups
- Gypsies and Travellers.
- Lesbian, gay, bisexual or transgender people
- People with a learning disability
- People with a mental health condition
- People who are homeless
- People who are in secure or detained settings

Alongside an overview report, CQC published people's experiences during the last phase of life, their unique needs and considerations and give suggestions about how change could come about to remove some of the barriers and improve services. These demonstrate that lack of awareness and understanding of those specific issues can be a barrier to good end of life care. Although written 6 years ago, many of these issues remain.

#### **What feedback have people given?**

- People in the most deprived areas were less likely to rate care received by their family member or friend in the last days and weeks of life as outstanding or excellent compared to those in the least deprived areas
- Carers for people living with a terminal illness in the most deprived areas were less likely to report that their family member had always been treated with dignity and respect than those in more affluent areas
- Carers were also less likely to feel that they had the right levels of support when caring for someone at home

There may be a number of reasons for these differences. It may be that housing in more deprived areas provides a less suitable environment for end of life care, or that people from more affluent areas can pay for additional support.

There may also be differences in local resourcing decisions and spending on services.

Evidence suggests that where you live can alter the outcomes for you at end of life and deprivation is a key influencing factor.

The End of Life dashboard looks closely at outcomes for people in different geographical areas of North East Essex, by deprivation indices as well as looking at ethnicity (although data entry for this needs to be extended further across the health and social care network). But it may be useful to focus on some of these groups to enable targeted and bespoke interventions.

#### **Community based interventions**

In order for people who chose to die at home (approximately 83% of those in North East Essex who indicated a preference on the My Care Choices Record (MCCR)) to realise their ambitions, community-based interventions are essential. This requires significant resourcing and some thought given to design and type of support. Whilst individuals at

end of life require medical, social and emotional interventions, family members and informal carers do too. This could be anything from support for their own mental and physical health to practical support such as shopping, cooking a meal, dog-walking and cleaning. A multi-disciplinary response, with good support from well-trained volunteers clearly makes a difference and expands capacity. An example of this is the Compassionate Companions service offered by Age Well East.

In 2021, Marie Curie published a report ‘Better End of Life 2021’<sup>3</sup>. Within the report it stated *“New models for delivering palliative and end of life care in the community will be needed to reduce pressures of the NHS and fulfil patient preferences for dying at home. Larger numbers of family members and carers will require support through dying, death and bereavement.”* Matthew Reed, Chief Executive.

Covid-19 has been given rise to a significant increase in deaths at home. Many as a result of long term illness or conditions and some unplanned due to Covid, with some being traumatic for the individual, family members and carers. This may have been the case due to sudden change in symptoms, fear about attending or being admitted to hospital, visiting restrictions in hospices and hospitals, lack of transport or lack of capacity within the health system. The report states *“In the future, if more people are to be cared for at home at end of life, attention is needed to ensure carers and family members do not become overwhelmed, as many have been during the pandemic.”* Informal carers can prevent hospital admission and help to meet patient choices if their needs are assessed and responded to for practical, emotional, and financial support.

Following deaths, the bereavement process was then complicated by restrictions in funeral arrangements, viewing permissions and support availability.

**Voluntary and Community Sector Assets** - how the sector is supporting people towards, at and beyond end of life.

### **St Helena Hospice**

The St Helena Hospice model of care philosophy is one of empowerment and self-management for patients and families, within a holistic assessment and treatment framework provided by two MDT groups surrounded with the support of a compassionate community and other health and social care external partners.

This model integrates health and social care approaches that enable access for more patients and families by offering care to referred patients between specialist and generalist services, while operating as part of a broader public health approach to supporting people experiencing end of life, including signposting to other external health care providers and agencies.

### **A Compassionate Community Approach**

Death, dying, loss, and care giving are not just medical issues, but societal ones, and as a society, we need to find ways of meeting the end of life (EOL) care needs of the population - now and in the future.

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<sup>3</sup> Better End of Life 2021, Dying, death and bereavement during Covid-19, Marie Curie.

The demand for EOL care is rising at a rate that professional palliative services alone cannot meet - an [independent report](#)<sup>4</sup> by Sue Ryder in 2021 revealed that the number of people needing vital EOL care in England will rise by 55% over the next ten years.

A Compassionate Communities approach helps to meet this need, built on the ethos of a combined Public Health Approach and Asset Based Community Development (ABCD), supporting the National Palliative and End of Life Care Partnership Framework (2016-2026) Ambition 6: Every Community is prepared to help.

Compassionate Communities recognise that everybody has a role to play in supporting each other during times of health crisis and personal loss, and that together we can make a difference. Local people, groups and organisations are essential assets that are willing and able to improve the experience of people at the end of their life and increase the resilience of the community to cope with issues related to death and dying and remove some of the taboos around it.

### **Compassionate Community Networks**

St Helena is mobilising a Compassionate Communities approach in North East Essex, by helping connect community assets and anchoring local networks of support with a shared vision: to improve end of life care and bereavement support for everybody.

In Q1 of 2022/23 St Helena led four 'co-production' workshops in Clacton and Harwich that provided a platform for local people and organisations to share their experiences, knowledge and ideas, and to highlight local need and priorities.

A 'Compassionate Communities in Tendring' network has been formed from these workshops, and further co-production planned that aim to increasing accessibility to EOL care by raising public awareness, reducing taboos and starting a conversation about death, dying and loss.

Compassionate Conversations awareness training is an example of a learning and development activity that will be made available by St Helena Hospice in collaboration with St Elizabeth Hospice, to support these goals.

### **Tackling Inequalities**

St Helena provides access to high-quality palliative care for all, irrespective of age, gender, faith, race or ethnicity. This includes addressing the health inequalities and accessibility issues experienced by many people who need their services. Their widening access programme cultivates and fosters links with minority communities to try and raise awareness of St Helena services.

St Helena views and values equality and diversity as a creative opportunity to embrace, respond to and be relevant to the local community. They recognise the need to create an environment where all patients, carers and their families feel they are treated equally as individuals; one that enables employees and volunteers to thrive and achieve their full potential.

A working group 'Addressing Inequality at EOL' has been established by St Helena Hospice to ensure that a strategic approach is being taken to embed this agenda. This will build on

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<sup>4</sup> Modelling demand and costs for palliative care services in England. A final report for Sue Ryder, February 2021.

the Equality Impact Assessment produced as a support document for the recent the NEECCG application for Children's Bereavement funding.

St Helena Hospice recognises and supports the Hospice UK Report: Equality in hospice and end of life care; challenges and change<sup>5</sup> which highlights the hospice sector strategy to 'Open Up' hospice care with the first of four pillars being to 'tackle inequality and widen access to hospice care. It identified key priorities:

- Timely access to care for non-malignant conditions
- Support appropriate to individual needs
- Improved understanding of unmet need in local populations
- Better collaboration and joined up working across health and care systems

The group functions as a community of practice, sharing a collective focus on improvements of practice, active learning through process of inquiry, and commitment to support implementation, and will support a Compassionate Community approach that brings professional and community assets together to deliver better health outcomes. The groups key objectives are:

- To support the NHS Equality & Quality (EQIA) Impact Assessment Policy framework
- To widen access and improve the experiences of individuals, and their families, accessing care with an end of life diagnosis
- To understand, evidence and articulate gaps in health care provision
- To build cases to address gaps in service, including accessing funding to support delivery where appropriate

St Helena Hospice is committed to addressing inequalities at EOL in collaboration with local healthcare providers, community partners and service users, through targeted outreach support and interventions. As such, it is also working with a cross Alliance working group, established by the EOL Board, that will focus on delivering the goals of the NHS Equality Delivery System (EDS2):

- Goal 1 - Better health outcomes
- Goal 2 - Improved patient access and experience
- Goal 3 - A represented and supported workforce
- Goal 4 - Inclusive leadership

Examples of St Helena working in collaboration with local healthcare providers, community partners and service users, to address inequalities, through targeted outreach projects such as Safe Harbour, Social Prescribing and Personalised Care, are described below.

### **Safe Harbour**

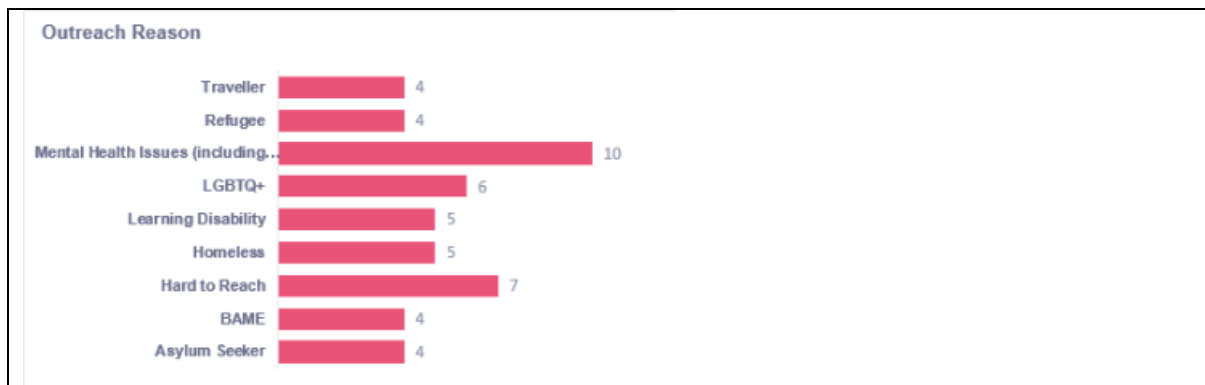
Data shows that access to end of life support and mortality varies depending on geographical location as well as levels of deprivation. In addition to this, for those who have limited or no access to a GP and a lifestyle which makes access to services challenging, access to bespoke end of life services can be difficult.

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<sup>5</sup> Hospice UK (2021). Equality in hospice and end of life care: challenges and change. London: Hospice UK.

The Safe Harbour project, run by St Helena Hospice and established in 2016, has provided support from an Outreach Clinical Nurse specialist role, who in 2021-22 supported 33 patients with complex end of life care needs. These patients required specialist outreach nursing support, as described in Diagram 1 below, included people with drug addiction, mental illness, learning disabilities and people with English as a second language. While this number seems relatively small each person required intensive and sustained outreach support. The circumstances of each outreach patient shown below (some patients had multiple reasons):<sup>6</sup>

Diagram 1: EOL Patients receiving specialist outreach nursing support from Safe Harbour 2020-21.



To date, the Safe Harbour project has helped to improve access of local people to palliative care in both direct and indirect ways including:

- Establishing trusting therapeutic relationships with local community representatives and organisations across the region from identified groups including gypsies and travellers, refugees and asylum seekers, the ethnic minority community, those with enduring mental health problems, substance misuse issues and adults with learning disabilities, and people from the LGBT community.
- Giving health and cancer awareness advice ensuring those from local homeless community, those with substance misuse issues and those with mental health issues have access to support that they are familiar with know and trust and are supported to seek appropriate investigations for their health concerns including screening and post cancer treatment follow up.
- Supporting people’s right to choice and autonomy at the end of life by offering either bespoke care, or a supported pathway into mainstream health and social care services.

The Outreach Clinical Nurse Specialist (CNS) was part of several work streams focusing on inequality, including the joint working group for mental health services, the Learning Disabilities Steering group, and the Outreach social prescribing Project Board, thus engaging with a wide range of community assets. The project re-established links with Colchester’s homeless charity, Beacon House, and Refugee Action, while working to tackle issues in the LD Charter, specifically the high level of preventable deaths amongst patients with learning disabilities and produced some safe and appropriate Do Not Attempt Resuscitation (DNAR) documents for LD patients. The Safe Harbour project was put on hold for the 2020-2021 period due to COVID pandemic, as staff were re-purposed.

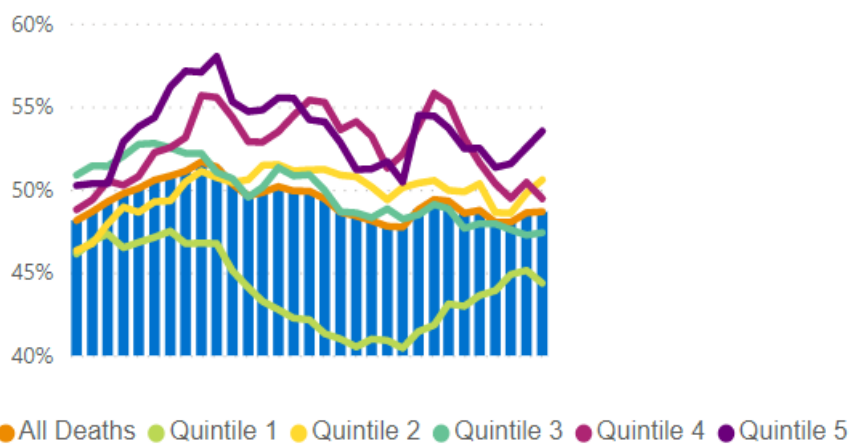
<sup>6</sup> Data from St Helena Hospice.



Whilst maintaining a small caseload the outreach CNS worked with identified under-served groups to understand the issues impacting on access to care, developing relationships and establishing pathways that are individualised to need. With this approach the CNS has been able to influence practice across the Hospice service and acts as an expert resource for clinicians across Hospice services.

Despite the success of the Safe Harbour project in improving access to hospice services, inequalities remain in EOL outcomes across the population of North East Essex. This can be clearly evidenced by the EOL Alliance dashboard which shows there continues to be an inequality between the least and most deprived quintiles in terms of the percentage who died in the last 12 months having their care wishes recorded on the My Care Choices Register (MCCR), with the most deprived quintiles also having the highest percentage of people dying in hospital. The dashboard shows that this inequality is narrowing over the last year as per the graph below (which is likely to be targeted intervention to address it).

% who died in last 12 mths on MCCR vs all deaths



This graph follows movement towards equity in EOL care in North East Essex over a rolling 12 month period, where quintile 1 is LSOAs in the most deprived 20% nationally and quintile 5 is LSOAs which fall in the least 20% nationally.

The capturing of advance care planning on the MCCR is associated with improved achievement of preferred place of care (PPC) as well as a reduction in emergency admissions in the final year of life (Accounting for Value Report 2020).

The formation of the Primary Care Network palliative care caseloads and increased collaborative working between primary, community and hospice care to manage their end of life population has further enabled the identification of previously unidentified palliative and end of life care need in the Tendring area in particular. Historically, although 60% of deaths in North East Essex were Tendring residents, they receive less palliative care resource.

Safe Harbour is a key project within a Compassionate Communities approach - a key part of a Compassionate Communities network in North East Essex that will improve end of life care and bereavement support in collaboration with local people, organisations and groups, across sectors, focusing on localities - e.g. Harwich and Clacton. With additional funding support recently received from ESNEFT, the scope of the Safe Harbour project will be widened over the next three years to enable various subject matter experts and workstreams to cooperate, with the aim to achieving positive equality outcomes.

The planned development of the Safe Harbour project will enable the project to focus on and address this unmet need. It is proposed the project would build on the work carried out to date but would increase its scope to include stakeholders from acute care as well as community and primary care services. This is consistent with the population health approach to end of life care being led by the EOL Alliance Board and seeking to improve the Die Well Outcomes that matter:

1. People are identified in the last 12 months of life
2. People thought to be within the last 12 months of life and their families are informed of the likelihood of death within the next 12 months sensitively and honestly
3. People's preferences for care are elicited and recorded during the last 12 months of life
4. People's preferences for care are respected during the last 12 months of their life
5. People's preferences for care are accessible to all parts of the health and social care system/end-of-life-care system
6. People at end of life are treated as individuals, with dignity, compassion and empathy
7. People's pain and symptoms are managed and controlled during the last 12 months of life
8. We are able to minimise inappropriate, unnecessary and futile medical intervention during the last 12 months of people's life
9. People at end of life have equitable access to flexible 24/7 end of life care services irrespective of the place of care or the organisation/s providing care
10. Families and carers are provided support during and after their loved one's end of life

Whilst hospice care is an important aspect of this support the vast majority of end of life care occurs outside of hospice services. By understanding and then working to address support needs within the community, Compassionate Communities will seek to improve access to care and therefore positively impact on the outcomes that matter.

To widen the scope of the Safe Harbour, a project manager will be recruited to deliver improved outcomes across workstreams, in partnership with stakeholders, with various subject matter experts being utilised to deliver the project. This may include data analysis expertise as well as clinical and social care resource, depending upon the issues identified by the project.

The aim is to deliver improvements over a period of three years, with the expectation being that after this time period the pathways developed to address inequity of access become business as usual and fully embedded.

### **Outreach Social Prescribing**

The overall aim of the Outreach Social Prescribing project is to improve outcomes for EOL patients within BAME and deprived communities. According to St Helena data the number of patients from BAME and deprived communities accessing EOL support is lower than other sectors of the community. Due to lower numbers of BAME citizens represented on the EOL dashboard it is difficult to track these communities across North East Essex. By adopting the social prescribing and compassionate community methodologies we can encourage more EOL patients from BAME and deprived communities to receive the support and care they need. These inequalities must be addressed if we are to improve outcomes for people at EOL and increase community resilience to cope better with issues related to death and dying.

This project commenced in September 2021 and has been delivered in partnership with local community voluntary sector agencies Community360 (Colchester) and CVST (Tendring), who have acted as host employers for two Social Prescribers - both contracted as 0.8FTE posts, and funded by a combination of Masonic Trust / EOL Board for a period of 9 months to completion of the data review for this report.

To fully understand the need for, and barriers to accessing, EOL services requires building up a trusted relationship with the communities and this in turn requires dedicated time to listen and fully understand. By being introduced by, and working in partnership with, leaders who are trusted within their communities the Engagement Officers will be in a better position to gain an understanding of the issues.

Working through the pandemic conditions proved to be a big challenge for the project, exacerbated by changes in staff within the host agencies, but we have started to see a real upturn in engagement and referrals stimulated by a Personalised Care directive from the North East Essex EOL Board to provide support for people in care homes - and additional funding for this purpose has extended the life of the project for a further 3 months.

At the end of July 2022, the numbers of people supported at EOL by the Social Prescribers was 144 in Colchester and 78 in Tendring.

A key part of the programme has been to engage more widely with under-represented communities and to capture their experiences of end of life care to improve accessibility. Supplementing the detailed information gathered by Healthwatch Essex in the Citizen's Voice section below, some important points emerge from working with minority community leaders:

- A taboo to have terminally ill relative in a hospice or care home
- Lack of trust of services (renewing the impact of historical health inequalities) and misinformation about them or their role
- Culture and religious rituals - this may include discussion of topics such as organ donation, significance of place of death, rites and customs, time sensitivities for practice and prioritisation of family relationships
- Language barriers

Colleagues advocate for cultural awareness training, collaborative decision making and monitoring of the impact of demographic change.

### **Spotlight - Example case studies**

Through the social prescribing programme, the range of experience is being exposed, reflecting challenges also highlighted through the Safe Harbour project, supporting people with complex needs.

- Practical support and assistance - help with shopping, financial support, and equipment
- Social Isolation - limited contact with known relationships and desire to reach out to wider community networks
- Communication - be that dedicated interpretation services or more general communication support to better access support

### **Personalised Care**

In October 2022, St Helena Hospice was commissioned by the Alliance EOL Board to enhance personalised care aspects within the EOL programme and address known inequalities locally by helping people access the My Care Choice Register.

This commission supported five of the six components of personalised care by enabling informative conversations with people thought to be in the last year of life, targeting areas of lower levels of register and deprivation, specifically to.

1. Enhance care and support planning (by making the MCCR discussions more holistic)
2. Improve access to social prescribing
3. Enhance patient choice
4. Address the inequalities in access to advance care planning in areas of deprivation

The initial funding allocation from the NEE EOL Board enabled the recruitment of a Project Coordinator role at St Helena. Due to the significant number of care home covid outbreaks in November/December, which prevented access to patients, the project reporting timeline for this allocation was extended.

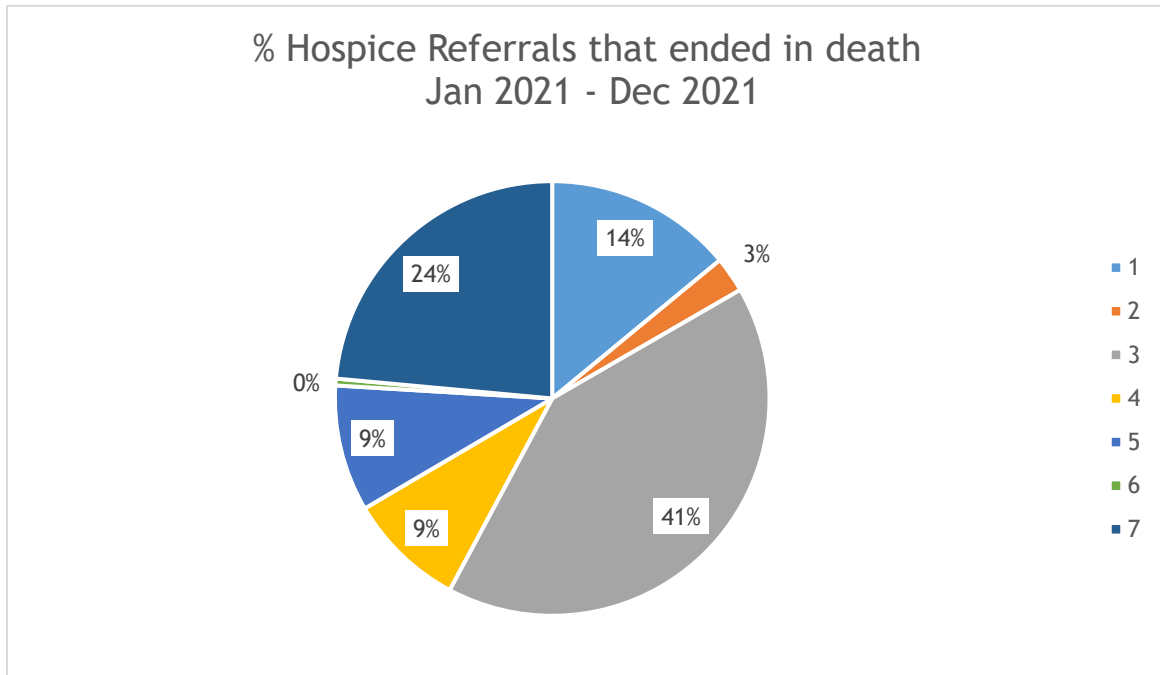
An additional funding allocation from the North East Essex EOL Board enabled the Project Coordinator role to be extended to the end of July 2022, and levered support from Social Prescribers at CVST and Community 360 - enabling them to conduct patient interviews, which would broaden their understanding of advance care planning and also encourage a development of social prescribing opportunities.

The following outputs were achieved to the end of July 2022:

- **73** referrals access to MCCR facilitated
  - additional 23 patient records can be added to MCCR as soon as their GP surgery has created these records
- **96** referrals interviewed and offered advance care planning discussion by the Project Coordinator / Social Prescribers
  - 161 referrals suggested by Care Homes - not all were willing/able to participate or died before they could be interviewed

- 18 social prescribing referrals made where relevant
  - While all care home residents interviewed were considered for additional social prescribing support, this was not relevant - or not accepted, in the majority of cases because of existing support provided by the care home or from family members. Some patients with dementia were unable to understand or accept additional help

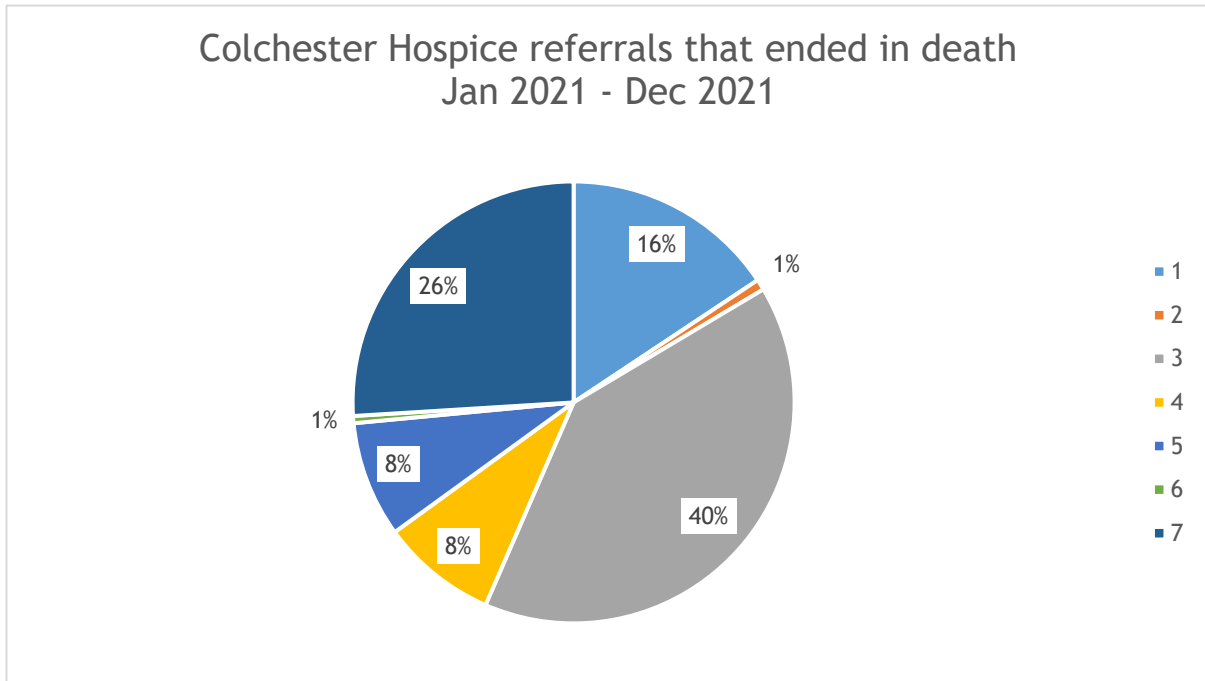
Chart below shows North East Essex Hospice Referrals that ended in death during the year 2021



(figures from above chart)

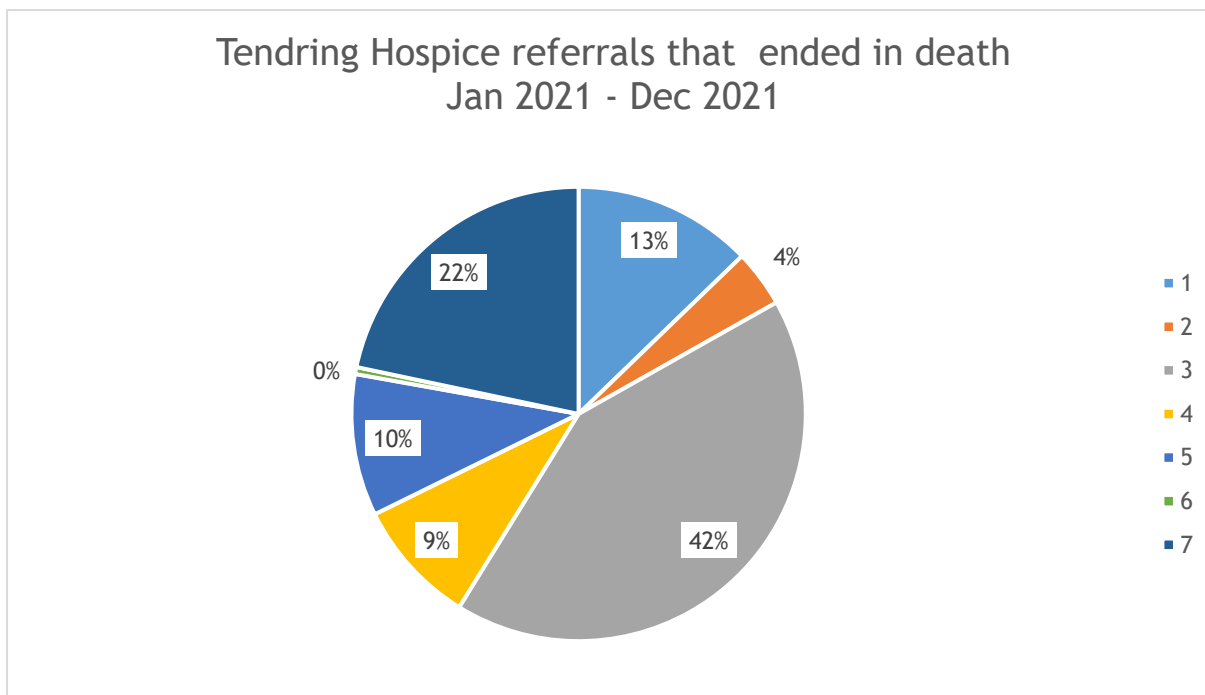
- 1 - Acute hospital (249)
- 2 - Community Hospital (47)
- 3 - At home (731)
- 4 - Hospice (155)
- 5 - No recorded location (167)
- 6 - Other/unknown (9)
- 7 - Residential, care, nursing home (418)

Looking at the combined figure of people who died at home and people who died in residential, care or nursing homes, this indicates that over 67% of hospice referrals that ended in death in North East Essex were 'at home'. Breaking this down further:



(figures from above chart)

- 1 - Acute hospital (120)
- 2 - Community Hospital (6)
- 3 - At home (307)
- 4 - Hospice (65)
- 5 - No recorded location (65)
- 6 - Other/unknown (4)
- 7 - Residential, care, nursing home (199)



(figures from above chart)

- 1 - Acute hospital (129)
- 2 - Community Hospital (41)
- 3 - At home (424)
- 4 - Hospice (90)
- 5 - No recorded location (102)
- 6 - Other/unknown (5)
- 7 - Residential, care, nursing home (219)

### **End of life Social Prescribing in North East Essex**

This further outlines the role of the EOL Social Prescribers and the impact they have on knowledge and access to choices at EOL.

The Social Prescriber works alongside St Helena Hospice and local organisations to support individuals who are towards the end of their life. The Social Prescriber is assigned on average two to four referrals a week, which can include need for support for things from shopping assistance to combatting social isolation. The Social Prescriber contacts individuals who are identified as palliative/end of life and are referred to them by various channels, such as the hospice, GP surgeries or word of mouth.

Social Prescribers work within a working group called Compassionate Communities, where they aim to bring organisations together to enable better access to EOL services. This group consists of local EOL organisations from representatives from the local hospitals, voluntary organisations, care providers and volunteers. This is still in early development so will continue to grow and develop to meet individual and organisational needs. The social prescribers are involved in EOL workshops with St Helena Hospice, CVST and Community360; they have regular meetings that discuss inequalities at EOL, as well as community outreach.

Regarding EOL care planning, Social Prescribers visit local care homes and speak to residents about the My Care Choices Register (MCCR), referred from SHH. During one-to-one conversations with care home residents, they ask what their preferred place of care and circle of support would be; should they be unable to say this themselves, they find out what is important to the individual and who they would like to have involved in their care. This information is relayed back to the hospice and the individual's GP surgery to be added to their MCCR entry. Recently, the Tendring Social Prescriber has been focussing on care homes in the Harwich area and is building good relationships with the care home management and staff, as well as residents.

Regarding death and bereavement, social prescribers and their CVS colleagues signpost individuals to bereavement support that is offered through local organisations including St Helena Hospice, Age Well East and CRUSE. CVST also has several bereavement and friendship cafés in Clacton, Jaywick, Harwich and Walton-on-the-Naze.

Social prescribers offer support for unpaid carers who may be struggling with their caring responsibilities by helping them to access services that can help them get respite or time out (with or without their loved one) to support their mental and physical wellbeing.

One significant issue identified is being able to get knowledge of what support can be offered out to GP surgeries. The Social Prescribing teams can be a possible bridge, as they are assigned to most GP surgeries in the local area, but sometimes a new face is not what people want to see when they have built up a rapport with someone else. The GP

receptionist or even the GP themselves can be the first person that gets told that an individual is struggling.

Another barrier/potential gap to accessing EOL care can be a lack of trust in the NHS. It was said that some individuals are concerned they are unable to access the right pain medication or get a level of care that would be received at the hospital. Social Prescribers suggest that care can vary between postcodes, as someone in the more deprived areas in Clacton may not receive the same level of care or support as in other areas.

Social Prescribers attend the Frailty working groups, led by the North East Essex part of SNEE ICS, which should enable prescribers to support and assist with plans going forward.

## Age Well East

Age Well East offers two services which have direct relevance to end of life care, as well as providing a range of services, activities and advice and information to enable people to have a better later life. The relevant services to this research are the Compassionate Companions Service and the Bereavement Service.

### **Spotlight: Compassionate Companions Service, Age Well East, supporting those who live alone**

The Compassionate Companions Service is an end of life companionship service provided with specialised end of life befriending. Its primary focus is on those people who live alone and are in their last 12 months of life. It is not clinical or advisory in any way, purely companionship. For most recipients, the service is delivered face to face in the client's own home, this is completely dependent on the location of the client and the availability of matched volunteers. If there are no local volunteer available, Age Well East offers video or phone calls, providing tablets if clients do not have a device themselves.

The assessment and referral process has been under review and recipient numbers are increasing, but there is still capacity within the service. There are currently nine clients and seventeen volunteers.

The majority of referrals in recent months are in coastal communities along the east coast of North East Essex. As most of the volunteers come from more affluent areas of the locality, there is sometimes a mismatch of availability of volunteers against demand.

Referrals can be made to the service in a number of ways: self-referral, family/friends or organisations - the main requirements are that the person is anticipated to be in their last 12 months of life; lives alone and has given consent to the referral. Referral can be made from the Age Well East website <https://agewelleast.org.uk/contact-us/referrals/> or by telephone: 0300 37 33 333. The service with after an assessment, and if eligible, matching with a volunteer. There is no need for a specific diagnosis, a high frailty score is sufficient for a referral to be made. The prospective client **must** know and agree to the referral being made and **give consent** for sharing of their information.

Volunteers are well trained and supported by the organisation. Training includes palliative, end of life and bereavement care; emotional support and signposting;



communication skills; recognising last days of life and verifying death; practical support after bereavement; 'I am dying, how long have I got?' - handling challenging questions; safeguarding. This is provided through NHS endorsed e-learning. All volunteers have lone worker training, monthly peer supervision meetings with coordinators and access to 1:1 support whenever needed.

Age Well East Bereavement Service supports people over 18 who live in Essex and are experiencing bereavement, feelings of loss and grief. They support people with guidance and information at this difficult time for up to 6 months, offering advice about bereavement and loss, support groups for those also experiencing loss or bereavement and one to one bereavement volunteer support. Support is on a 1:1 basis, primarily over the telephone. For those who live outside the area or have specific needs or interests, Age Well East is able to refer on to other organisations, with consent.

## **Carers**

It is well known that in most cases those caring for their loved ones put the needs of the person cared for before their own needs and often ignore their own needs - this escalates towards the end of life. Carers can often ignore offers of help. There are a number of excellent organisations supporting carers across North East Essex and this section services to spotlight good practice and some of the challenges carers face at end of life of their loved ones.

In North East Essex we have a robust and strong hospice which supports people and their families towards the end of life and offers a range of services. A large number of carers/relatives support their family members and friends with life limiting illnesses and have no contact with the hospice. Unless directed towards carers' services by GPs, friends or the hospitals, people are sometimes unaware of the type and range of support available.

Language remains a problem - asking 'are you a carer?' is often not appropriate as people do not give always themselves a 'carer' label. GP and hospital identification of carers and their support needs is therefore critical. As the loved one's condition deteriorates, it can be difficult to access GP services in the usual ways, a trip to the surgery or finding time for a confidential phone call can present significant challenges.

It is important that carer support needs are focused on the carer as a whole person, not on the condition of the person they are caring for. There is often the need to reduce feelings of isolation, to reduce financial pressure, support remaining in employment, help to maintain social and pleasure interests and connections. For the carer, these can be seen as luxuries but maintaining some of these personal support systems can ease the grieving process and the sense of a vacuum when their loved one reaches end of life. Small interventions with a high impact. The Essex Carers Support is a good example of this. A good carer's assessment will help to unravel some of these issues but contact and engagement with organisations such as Carers First, Action for Family Carers and Essex Carers Support can enable quick and easy access to bespoke support.

### **Spotlight - End of Life Case Study**

Max and Mel have been married less than a year and have been providing informal care and support for Mel's father who has poor health and is becoming increasingly frail. Just recently Mel was herself diagnosed with a terminal illness and has been advised that her condition will deteriorate significantly within the coming few months.

Essex Carers Supports 'Time 4 You' project has supported and assisted Max to focus on the impact that caring for his father-in-law and now also his wife is having on him. He was helped to access self-care resources and ongoing support services. Importantly, he was given opportunity to talk through his own feelings and concerns.

He felt particularly concerned that the pace of change in their circumstances, particularly following so soon after Covid restrictions, mean that he and his new wife have not had opportunity to build positive memories of their marriage.

Max received a 'Time 4 You' grant and used this to arrange a simple weekend away for them both. Max reported afterwards that this had made an enormous difference to how he was feeling and had provided an opportunity for them, away from home, to talk openly together about their current situation. He said that until his contact with Essex Carers Support, all conversations had focussed on his father-in-law or his wife and that no-one had spoken about the impact on him. Max is now accessing ongoing support in relation to his caring role.

More carers workers in hospitals would help, one worker alone may miss opportunities to enable access to carer services. For example, in hospitals' oncology departments and outpatients, where end of life is identified, who is talking to the person who brought the patient to their appointment?

In consultation with local specialist support services for family carers, it is clear that their relationships with residents often begin at an earlier point in diagnosis of any long-term conditions and can remain active for several years. Referrals at end of life are rarer and connections with palliative care come when the carer and their loved one experience change. This reinforces the correlation with other domains, especially Stay Well and Age Well, as part of a process of relationship building. The support required at end of life can become very intensive and the relationships with VCSE services become more acute.

## Communities working with care homes



Care homes are an important part of the infrastructure of the Die Well domain that is comprised of both voluntary and community sector and commercial assets.

Over the last two years, Colchester Borough Council have been working closely with FaNs (Friends and Neighbours), a charity specialising in bringing communities and care homes closer together through networks of friends and neighbours. Together with other partners, a range of programmes have been developed to improve physical activity and engagement between care home residents and the wider community with results improving social, wellbeing and health outcomes.

FaNs exists to keep older people in Essex care homes involved with and connected to their wider community. With initiatives such as the Wishing Washing Line - matching older adults with people who can help fulfil their wishes, special events, including trips to Remembrance Sunday memorials, and activities such as Care Home Bake Off contests.

For the Valentine's Day Bake Off in 2021, FaNs and Colchester Anti Loo Roll Brigade, with funding from East of England Coop, Tesco and Asda worked with twenty care homes to submit a baked cake, cookie or cupcakes with online voting for people's favourites - 3,799 votes were cast, and the winning home received a trophy.

Several physical activity programmes have been operating with the support of the Local Delivery Pilot and between April 2021-September 2021 the FaNs network and Mr Motivator Club joined forces with the LDP to organised four live interactive zoom sessions for 70 Care Homes across Essex with more than 300 residents able to access them.

Projects have also sought to bring people in contact with nature, through partnering with **Together We Grow**. Co-ordinating a six-month growing programme for 20 Care Homes who received 73 packs of vegetables and plant seeds. The Care Homes met monthly via Teams and the programme ended with a celebration at the Big Garden in Highwoods where residents brought what they grown and cooked up fresh vegetables into a meal to share. Residents with limited mobility were able to watch seedlings grow in their rooms and gain pleasure from the process.

By engaging with a range of opportunities, residents are supported to access a better quality of life and more connected social networks, with tangible benefits for wellbeing.

### **Spotlight - Care Home Commonwealth Games**

In the Summer of 2022, over 80 Colchester and Tendring care home residents visited the Colchester Sports Park and took part in the Care Home Commonwealth Games organised through the work of FaNs and Colchester Borough, funded by NHS Suffolk and North East Essex.

The residents lived in eleven different homes across Colchester and Tendring, with the Games designed to provide opportunities for people to be more active and access new environments. The range of events included penalty football from Colchester United FC, cycling from Wheels for All, boccia, curling and dance with Sport for Confidence, discus and shot put.

Organisers highlighted the importance of the benefits of physical activity on mental health, with all activity tailored to the needs of residents with varying levels of mobility and experience. Care home staff have spoken of the enjoyment for residents and the desire to continue to offer such events more regularly within the home.

### **HILL Project: Bereavement and Friendship Cafes<sup>7</sup>**

HILL (Helping Independent Longer Lives) friendship cafes are weekly groups for anyone who feels isolated, wants to make new friends or has experienced bereavement. There are a range of activities and guest speakers are invited to every session to provide important, insightful or entertaining information or demonstrations. Outings are planned throughout the year.

The cafes have formed a basis for many new friendships, direct support and the opportunity to go out to a safe place where there is empathy and understanding among members about living with bereavement and loss. Members have described the cafes as a 'lifeline' and a place to meet new friends and share emotions. Many members have formed firm friendships, meet outside the groups for coffees, lunch and even go on holiday together.

#### **Quote from a volunteer at the Harwich Friendship and Bereavement Café:**

"The Friendship and Bereavement Cafe is a place where lonely people meet, make friends that turn into old friends, sharing good times and bad."

If members are experiencing considerable difficulties with any aspects of their lives following bereavement, the cafes' volunteers are able to sign post them to other organisations or services which may be able to help them.

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<sup>7</sup> <https://www.cvstendring.org.uk/friendship-cafes>



Friendship and Bereavement Cafes and Fun and Friendship Cafes are held weekly in Clacton, Harwich, Walton and Jaywick. Interested people do not have to book a place but can call ahead to make sure that someone is able to meet them, and confirm that the group is taking place at the usual venue and not on an outing somewhere.

### **Covid and the role of collective commemoration**

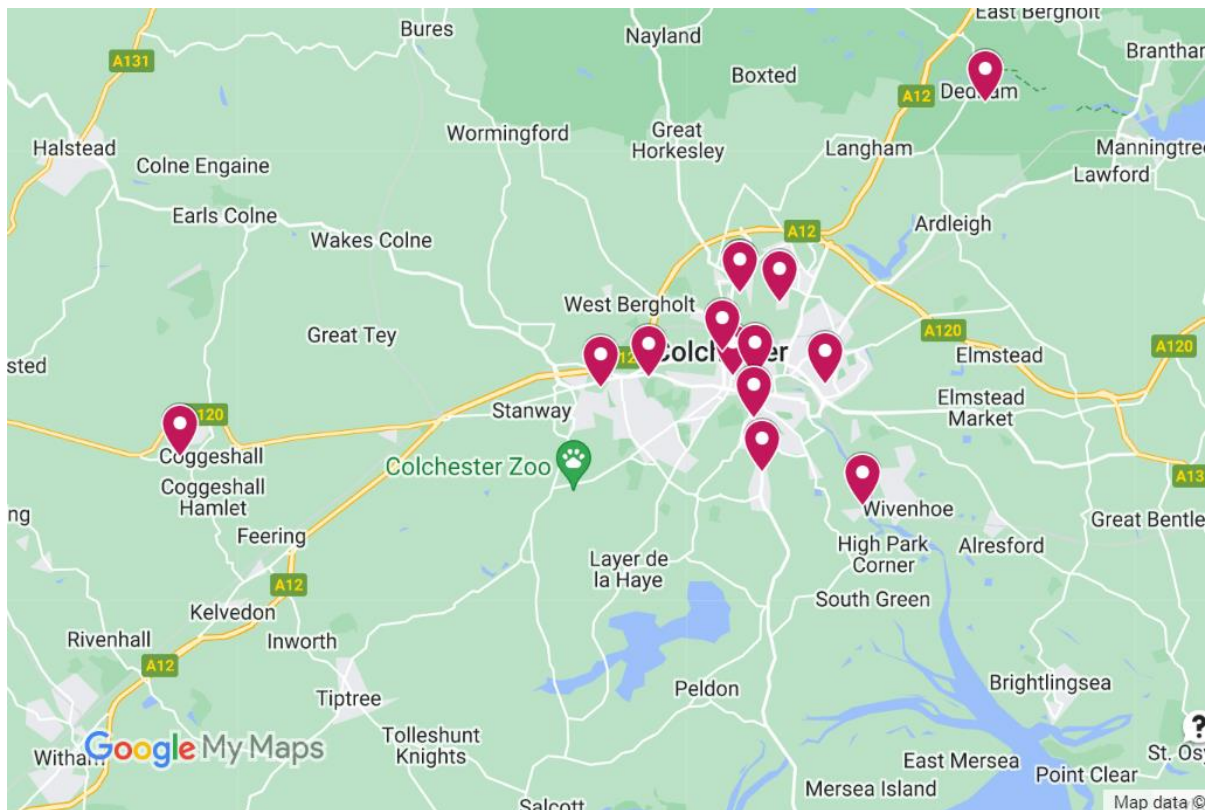
Entitled ‘Commemoration: Remembering and celebrating the loves, lives and losses of the last two years’, the event took place at the Mercury Theatre in March 2022. With readings, poetry, music, dedications from leaders of religious faiths and memorial acts, such as the lighting of candles, the event brought together leaders and community members from different walks of life.

Feedback from the event described it as a ‘combination of sadness and gladness in equal measure’ that created a mood of ‘rightful remembrance’, and for another attendee that ‘as a family, we were also moved by the whole occasion, which was such a thoughtful and well-balanced programme, professionally delivered. It made us feel humble and proud on behalf of everyone who gave their best to contribute.’ Provision of a focal point for grief and celebration of the support people gave during the pandemic was significant as a shared experience.

The ability of communities to remember and collectively process their feelings in different ways extols values embedded in the Compassionate Communities approach but are less prominent outside of conversations about the pandemic. They do occur, in more contained localities or networks but could benefit more people with openness and increased opportunity.

## Asset Maps

Throughout the research phases of this report, we have been confronted by a lack of promotion of the role that groups may play in supporting end of life. It is particularly striking that many services that people are signposted to, through online directories and guidance are national or regional helplines and networks. In comparing these findings with Charity commission records and other sources of data, very few can be pinned to locations in the Borough of Colchester or adjacent to it, as shown in the map below. The map identifies VCSE groups, excluding care homes. Eight of the 14 pins designate bereavement services. The remaining pins identify St Helena, services based at Colchester Hospital, including Macmillan, counselling services for people diagnosed with a life limiting condition under the age of 40 and groups like Coffin Club.



Whilst many more groups will contribute to the lives of people at end of life, this is not openly or publicly recognised and signposted.

## Citizen's Voice

To ensure that the citizen's voice could be gathered effectively and productively, the engagement method we used was a qualitative approach, implemented via two different work streams. We would like to extend our gratitude to the participants who kindly gave up their time to take part in the project. We hope you found it empowering to have your voice listened to.



### Interviews

In order to gain a more in-depth understanding of barriers, cultural factors and to hear more detail about people's experiences, a number of 1:1 interviews were conducted. These involved reaching out to various organisations and individuals within the intended areas. Participants consented to taking part and having their conversations recorded. These conversations were then transcribed and analysed to produce some key themes for both geographical areas.



### Case Studies

Case studies are used frequently throughout this report to spotlight services and understand community response to end of life.

Through our engagement, the following themes were identified:

- Signposting or awareness
- Understanding and empathy
- Lack of communication
- Taboo topic

Many families are at a stage of grieving where it is too sensitive a subject for them to share their story, therefore this was a barrier we had to overcome to find willing participants.

## Who have we engaged with?





## Signposting/awareness

It has been identified that there are many community based end of life support services available in both Colchester and Tendring. However, a reoccurring theme throughout our engagement is the lack of signposting to these services amongst the general public and in some instances, the healthcare professionals.

*“A theme that was passionately spoken about during the last café meet was the fact that the families received a diagnosis from the doctor and that’s it. There is no signposting, they don’t know what they’re dealing with, they don’t know what path they’re going down, they have no support and it’s by pure chance and by getting out into the community that they find places like Carers First who can offer advice and support.”*

- Project participant

*“Even though there are social prescribers attached to GP surgeries, there has been a huge breakdown in that route of communication. The communication from the hospital to the doctor is very poor, leaving the family in a state of confusion, leaving them in a frightening situation themselves. The GPs as a matter of course should be signposting people but they are not.”*

- Project participant

A participant, and a new service provider remarked that if she is finding (navigating the healthcare services) very challenging, then it must be even worse for the end user. This is an area being addressed within the King’s Fund regarding the issue of ‘non co-ordination’ of services who should be working together in a person’s final days of life. The King’s Fund (2022), [Dying matters - which is why we need to deepen our understanding of end-of-life care | The King's Fund \(kingsfund.org.uk\)](#). The King’s Fund supports the Health and Care Bill to enable greater collaborations between health and care organisation to deliver integrated care (23 March 2022). [The Health and Care Act 2022 | The King's Fund \(kingsfund.org.uk\)](#)

*“Sometimes you wish you had a little booklet that told you ‘You are a carer of an elderly parent, please phone this number if you need to’.”*

- Project participant



**Participant's responses to lack of signposting or awareness**



## Understanding and empathy

Participants agree that there is a lack of understanding and empathy. Patients with health concerns have shown better outcomes from an empathetic approach. A lack of empathy can negatively impact patient care leaving those receiving medical care feeling frustrated, neglected and confused about their treatment.



*“The hardest part was trying to convince the doctor that mum was dying”.*



- Project participant

*“A gentleman was very tearful when retelling his experience of a conversation with a social worker who was talking to him in acronyms. He said that he gets butterflies in his stomach every time he has to speak to her because he doesn't understand what is being said to him. He's left feeling very confused.”*

- Project participant

Another example of this was a medic who saw a 91 year old patient in clinic and offered him a seat. The swivel chair had no arms and wheels on its base. When highlighted by the patient's daughter that this style of moveable chair wasn't ideal for her elderly father, whose legs were very unstable, the doctor responded *“Yes, but it is good for me”*. This chair caused a significant amount of stress for the patient who was very slow to move for fear of falling off. As a result, the length of the appointment was unnecessarily longer than needed. A poor experience which could have easily been so different.

A further example of a dismissive response from one doctor seeing the same patient (who may have had a broken hip) stated *“Well, he wouldn't be able to walk on it if he'd broken it”* but given his use of a walking aid, his carer highlighted that he may well have been able to.

Carers are often equipped with a vast insight of the person they are caring for, especially if it is a family member, but can often feel undermined and their knowledge of the patient dismissed by professionals.

*“No, I'm not qualified, but I've had experience in my life of looking after my mum, my nan, and many different people. And life is the teacher sometimes, not what qualifications you've got.”*

- Project participant

Consideration should be given to the emotional impact and challenges of caring for a loved one. Carers deserve more recognition.

*“You’ve got to gear up and fight the fight. And because you’re fighting the fight anyway, even doing something like this is extra.”*

- Project participant

*“(Patients) They’ve got to have someone in that corner to fight for them, because otherwise, they get lost.”*

- Project participant

## Carers

Unpaid carers have many different caring roles. Working with both families who are active carers and those who have lost a partner. An ongoing service is offered to those, predominantly elderly, who are still registered with Carers First. A bereavement service is available on their website.

A monthly session is offered to support carers in Essex, aged 18 and over, offering online help and advice, as well as practical and emotional support. The camaraderie has great value as carers can see that there are others out there experiencing similar struggles.



*“I wished I hadn’t waited until I was in crisis before contacting Carers First. They’ve been an incredible help to me”.*



- Project participant

Carers First then have the opportunity, with permission to advocate for the carer, to speak to the social worker and obtain the information for the carer.

## Ethnic minority groups

In 2012, the organisation Help the Hospices, found that those from ethnic minorities, and with diseases other than cancer, could be especially disadvantaged in their access to specialist palliative care services. The organisation estimated that 92,000 people who could benefit from palliative care each year do not receive it. Research commissioned by the charity Sue Ryder in 2013, showed that people were willing to accept the prospect of a painful death if it meant being with their loved ones at home.

It is also the case that attitudes to pain and pain relief can vary with ethnicity, faith and generation. Some refuse pain relief because they want to retain some level of consciousness when they are dying or because pain has religious or spiritual meaning.

Islamic death rituals can be extensive and in-depth. When a Muslim is nearing the end of their life, they are kept at the heart of their community. If possible, they should die at home with their children or other members of the family around them which is seen as their duty to a dying person.

An Imam whose role is to officiate and lead prayer and other services, is considered an essential part of Islamic practice and also take on a role of supporting the community. Though there is no strict stipulation in Islam that an Imam has to accompany the dying person, the family greatly appreciates having prayers and rituals performed. In Colchester Imam Bashir Goni is well respected in the Islam community.

*“There are a lot of (Muslim) rituals and it’s very important to have that person. In Colchester we are lucky enough to have Imam Bashir Goni. We all rely on him as he’s got the knowledge of the Islamic ritual. We all depend on him. He did help.”*

- Project participant

*“If people are nearly dying at that time, we always involve the Muslim people...as soon as a person dies, then he or she should not be handled by a non-Muslim.”*

- Project participant

### **Bangladeshi Women’s Association**

With ethnic minority communities expanding in and around Colchester, there is currently an inadequate provision for the culturally specific needs of women and children. These are a vulnerable minority of people that are frequently isolated from the community and, due to the cultural differences, are increasingly becoming housebound due to language barriers. This is having a consequential effect on their children. Concerns have been growing in relation to community development and efficient access to services and social welfare. Their outreach work confirmed that everyone agreed ‘something needed to be done’ and members of the association meet every Monday for a lunch club where a lot of elderly people attend.

*“The main aim for this group is for our members to be able to access all of the community services. We are still fighting, struggling hard to get access to the services...there are a lot of things that need to be done. It’s just no good talking and discussing. None of our people are on that table. We are that forgotten citizen of North-East Essex.”*

- Project participant

### **African community**

Participants agreed that improved training is needed for health and social care professionals to enable them to provide appropriate care to BAME groups, avoiding assumptions and stereotypes and listening to patients and their families about their needs and preferences at the end of life.

*“I’d rather be alone and die in my own home, drink my own glass of fresh water than die in a hospital.”*

*“I don’t have the knowledge about what services are on offer and I don’t trust services due to my previous experiences.”*

- Project participant

Participants were mindful that conversations about death and dying can be difficult in many African cultures, possibly because many believe that the power to give and take away life belongs to their creator. A participant shared that most carers believe that once their loved one is dead, their relationship with palliative care services ceases. This should not be the case, but it may explain the surprise many express when contacted for grief and bereavement support. Despite their surprise, the majority are pleased to talk about the death and dying experiences of their loved ones. Some seeing it as an opportunity to honour the dead.

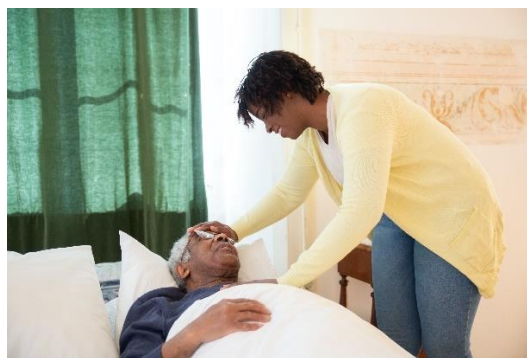
*“I don’t want to die in hospital or a nursing home, I’ve worked in both and have seen what goes on and there is nothing that I can see that they’re offering which is better than when you have your own family looking after you coming up to that time.”*

- Project participant

Among our African participants they agreed that faith beliefs, emotional issues, family dynamics, and insufficient knowledge are closely connected with regards to decision making about palliative care and hospices. They felt that there is an opportunity to improve communication about end of life services and this can be done through the African church. One participant shared what ‘dying well’ meant to them:

*“It was important that my mum’s life wasn’t just kept alive by artificial means prolonging her suffering.”*

The Community Ambition Funding Programme has been created in partnership with the Suffolk and North East Essex Integrated Care System, with a very specific criteria, to reduce health inequalities in ethnically diverse and deprived communities, impacted disproportionately by COVID-19 in Suffolk and North East Essex.



## Empathy and communication

### Case Study

Fifteen years ago, Martin received a kidney transplant then developed diabetes from his medication. With deteriorating health he was transferred from Ipswich hospital to Colchester hospital, a lot of time spent in excruciating pain. The medical team were unable to help in any areas other than dialysis. Martin's toes turned black, he was in excruciating pain, but it wasn't until two weeks later, when a Diabetic Nurse highlighted that something did need to be done. The ward ran out of his pain medication and his family made a complaint to the ward staff - they were given the Pharmacist's number and told to ring him. The family called the hospital's main reception to be told that the Pharmacist's number did not exist.

*“It was the fight and the shouting I had to do whilst he was at his lowest ebb, I received phone calls during both day and night. Martin was screaming in pain.”*

The medics advised that two of Martin's toes should be removed and there was a possibility of losing more of his lower limbs “until a good blood supply was found”, and he “may wake to find a below the knee amputation on both legs”. His pain medication was kept up but was not effective - only Paracetamol was offered, even though he was due to receive morphine. Martin made the decision he couldn't cope any longer and requested to withdraw from treatment and family felt like they had “signed his death warrant, albeit we knew it's what he wanted”. There was no support given. Martin believed that he was going to die in hospital in pain. His lasting wish being to die at home pain free.

*“Hearing a grown man screaming in pain is heart breaking and I'll forever feel traumatised by that.”*

The family were strongly advised against Martin receiving end of life care at home. This was against the family's wishes, believing they had sufficient support in place including being nurse trained. The hospital reiterated that there would be no additional support provided once he'd left hospital.

*“It's a very lonely and scary place when thinking how we are going to turn him in the bed, clean him, administer medications, when you know there isn't anyone you can talk to.”*

The participant feels there is a need for a joined-up approach to ensure the correct care is given, ie., an interconnection between the various departments and the patient. The need for more conversation around when end of life is, making sure people have the best opportunity to fulfil their wish of where to die, wherever possible, and sufficient medication is available to ensure an individual is comfortable and pain free at the end of their life.

Healthcare is an area where empathy really matters.



*“I cried down the phone, because I just want someone to listen to me.”.*



- Project participant

Several participants acknowledged a service offered by ESNEFT and were very appreciative of their end of life volunteers called ‘Butterfly Volunteers’ as spotlighted below.

### Spotlight

Butterfly Volunteers (BV) is a service offered at an acute hospital, ie., Colchester General Hospital and Ipswich Hospital based service for patients in the last twelve months of life. Complementary therapy, benefit advice and a variety of activities are available if the patient is well enough to participate. They can signpost as well being very knowledgeable about community services. The BV are available at both sites and they are looking at expanding this service which will be run five days a week. The service is for people within the last twelve months of life so when they come into hospital there is someone who can sit with them. Volunteers are currently speaking with those people who are at their end of life but they are also able to sit with people who have had strokes, living with dementia etc., and offer support for relatives too - giving them a break from the bedside. The expanded service will include bridge services within the community given the challenges that carers struggle with, ie., taking breaks. Charities are available but support is limited.

If patients are recognised as dying, they are added onto a system called Watchpoint. Volunteers will be signposted to visit these patients. An extensive volunteer recruitment drive will be taking place to support the expansion of the centre, which has been given some extra funding until September 2023. The vision is to roll out this service to community hospitals ie., Clacton, Harwich and Suffolk.

Feedback received from patients, relatives and BV from Colchester include:

*“The Consultant who was doing his rounds with junior doctors told me that “Butterfly Volunteers do a wonderful job.”*

*“K was quite agitated and seemed uncomfortable which I reported to the nursing staff. I also asked them to please give him mouth care as his mouth was very dry. He seemed to be calmed by my presence and my talking to him.”*

*“I introduced myself to P and sat quietly with him. His partner arrived and I told her about Butterfly Volunteers. She was very pleased he had someone with him and thanked me for the visit.”*



## Taboo topic

There is a cultural trend, and the concept of dying is the barrier, a taboo subject meaning that many find challenging to talk about. An opportunity to desensitise death and dying is the Coffin Club located in Colchester. Encouraging people to talk about their end-of-life choices is thought to be one way of moving towards better end-of-life care. Death plans and choices are also constrained by who you are, where you live and what you are dying from.

*“There needs to be a more honest conversation within primary and secondary care when people are entering the last years of their life to avoid the mess that families inherit when a loved one dies”*

- Project participant

### Spotlight

Coffin Club became a registered charity in 2019, the first Coffin Club in Essex, was started by three ladies from the local area, who all share the goal of providing accessible information about end of life options available to everyone. It provides the opportunity to talk about what is traditionally a taboo subject, helping people to reclaim a participatory relationship with death and build strong, supportive communities where people can have frank conversations and reflect on their future. People are empowered and support is given to help them understand their choices and options for low cost funeral planning. Sessions include the opportunity to listen to guest speakers or the chance to decorate their own low carbon footprint coffin. They advertise on numerous social platforms as well as more traditional forms of advertising - word of mouth. Barriers to accessing Coffin Club include lack of transport and self-imposed isolation from members of the community.

Pre-pandemic, Coffin Club attended Colchester and Clacton Older Persons fairs run by MPs. They arranged one off events at St Helena Hospice, which included an end of life Doula and a film showing. With this year's focus being Dying Matters Awareness Week, the club were able to financially support Liz Rothschild's play 'Out of the Box'. A Death Café and a creative event, on board the sailing barge moored in St Osyth's boatyard, which involved creating a memory event so people brought along something from their loved one or create something for your family to pass down. Cost wise, Coffin Club have been quite successful in grant applications as, though affiliated with, they are financially separate from Coffin Club UK.

Coffin Club funded two end of life Doulas and Soul Midwives (similar to an end of life Doula but slight variation as to what they do). They provide non-judgemental/non emotional support to a person who is terminally ill and the family to a certain extent.

### **Spotlight on Coffin Club continued...**

“From a palliative perspective, once someone has a terminal diagnosis and they’ve decided they want to be supported to die in their own home, sometimes their voice becomes lost. Families will be there supporting them but a number of support services, ie., district nurses, hospice at home, different entities will be coming and going and that person and the family become disconnected.”

A solution to this may be to involve the family more, not necessarily overriding the patient’s decision in any way but having a realistic conversation about what their hopes may be for their (celebration of life) funeral, what that would that to look like, ie., a preference of music to be played and poetry read. Jenny Edwards, a funeral celebrant may ask the family questions such as ‘what school did your mum go to’, or ‘what was your mum like as a teenager’ and families are often unsure.

From the Coffin Club’s perspective, when people die there’s a sense of urgency (by society) to get rid of the dead body. Coffin Club promote that people should have the chance to grieve and if they want to keep the body of their loved one with them then the community should support this. Historically (during Victorian times), this was normal practice, however, in modern times this has now been pushed to the fringe of our society. Death used to be at the heart of our community, the person who delivered the babies laid out the dead. This still happens in Ireland - short amounts of time are spent with the funeral director and then the bodies are brought back home.

## Role of the GP

Of those participants that wanted to discuss their end of life plans with their GP, they agreed that a barrier to achieving this has been a reluctance to visit the GP surgery due to the recent pandemic. Additionally, the challenges of booking a doctor's appointment are frustrating. A Care Advisor is available at Prettygate Surgery, part of a 'GP Care Advisors Service for North East Essex'. This service can only be accessed via the surgery's main reception number which forms a barrier given the difficulties of not always being able to get through.

“They're doing what they've got to do to survive and get through. But the way the system is set up, the GP is the first point of call and it's all funnelled through them while they are short of numbers and are struggling”.

- Project participant

Project participants agreed about the complexities surrounding end of life conversations and the challenges this may pose to a GP, ie., when is deemed an appropriate time to discuss this issue with their patient: whilst the patient is well?; having just received news of an illness which the medics hope to cure?; and how does a doctor reach out to all their patients? It might be that a doctor's personal experience, thoughts, emotions regarding their opinions on end of life will also impact the conversations that may or may not be had with their patients.

A surgery that is considered to have robust systems in place is the Riverside Medical Centre, which covers the Mistley and Lawford areas. They actively record a patient's end of life request on the My Care Choices register. A letter is sent out to the patient in their last year of life and a follow up phone call from the GP is made two weeks later. Gold Standard Framework (the UK's leading training provider for generalist frontline staff in providing a gold standard of care for people in the last year of life) meetings are held on a quarterly basis. Their lead GP meets Primary Care Networks to share good practice. A patient's PPC (preferred place of care) is also recorded on the doctor's spreadsheet.

Most GP surgeries in North East Essex have a Care Advisor working with them which any patient can refer themselves to via their GP surgery. Patients are signposted to Social Prescribers or Care Advisors who can provide support with practical or wellbeing needs.

Several Project participants who are registered with the Ambrose Avenue GP surgery in Prettygate, struggled to access this service if they were unable to visit the surgery in person or are not computer literate. The alternative being to call during surgery opening times where there can be a lengthy wait before speaking to a receptionist. Participants registered with Riverside Health Centre, Manningtree, found the Care Advisor service of benefit in addition to being able to speak to another member of this team about their financial matters.

Lawford Surgery, Manningtree, does not have dedicated Care Advisor working with them so participants registered with this surgery are signposted to St Helena Hospice for end of life information and support.

## Hospice care

The majority of project participants are aware of their local hospice though, of the older participants spoken to, they have limited access to information online. Therefore, are unaware of the extensive variety of services offered by the hospice and this information had not been shared with them at their GP. For example, St Helena Hospice services also include SinglePoint; Virtual Ward and Hospice Education.

### Spotlight

St Helena Hospice is a local charity that provides care and support to patients and families facing incurable illness and bereavement. Offering care and helping them make their own choices and live with dignity. They work closely with the hospital, district nurses and other health and social care services and charities to ensure the right support is provided to patients and families. Providing a wide range of services, not just in the hospice but in people's own homes, or care homes, and over the phone with their 24/7 advice line, SinglePoint, and if there's an urgent need the team can make an emergency home visit. Many of the people they support are cared for across the community by their Hospice in the Home nurse specialists supported by the wider hospice team including doctors, physio and occupational therapists and family support workers and counsellors. Patients nearing the last weeks of life may also be supported by their Virtual Ward who provide care and support at home to the patient and their family. At the hospice they provide 24 hour specialist care in their 18 beds for people who have complex needs that cannot be managed at home.



*“If I needed help with my aunt towards the end, I could ring the hospice to help, which I did, and they were marvellous.”*



- Project participant

### Spotlight

Mistley Manor is a private, family run care home in Mistley on the outskirts of Manningtree and an example of offering good end of life care.

*“I asked the Sister of the Stroke Ward, who had a friend staying here, if she could provide any training for the team here. Sadly, her friend had passed away here and having just gone through the process here with us, her response was ‘there was nothing she could teach the team here’. Praise indeed!”*

- Project participant

### Spotlight

East Suffolk and North Essex NHS Foundation Trust (ESNEFT), which includes Colchester Hospital within our engagement area, have specialist teams ie., a palliative care team who support the ward team. They also work closely with the discharge team, occupational therapists and chaplains, also working closely with community teams such as St Helena Hospice.

- Julia Thompson, Consultant in Palliative Medicine

### Inequalities and barriers to accessing end of life provisions

The Essex Partnership University NHS Foundation Trust (EPUT) scoped the North East Essex area, highlighting a diverse range of services in terms of mental health services, have some dementia units, some substance and alcohol abuse services and general mental health - which all at varying times tap into end of life care.

A large scale external audit of staff identified that people with alcohol and substance misuse were often dying of a long term medical condition but because they were recorded on the system as an abuser, don't receive the same access to care that they would have got had they solely had the long term medical condition.

Some of the work that EPUT have been doing with their system partners ie., ESNEFT, has been focussed on patients admitted with substance misuse and suffering, for example, renal failure. They'll be under the renal surgeons but how will they be signposted to best practice of care. A guidance/pathway has been developed to support this and will be launched imminently. This guide has been coproduced with Dr Fiona McDowall, Consultant Old Age Psychiatrist and End of Life Medical Lead EPUT.

Dr Nicky Sexton and Dr Thulavavenkateswaran from St Helena Hospice supported some of EPUT's dementia services to obtain the Gold Standards Framework training, eg. the Tower Ward in Clacton Hospital is now a Gold Standards accredited ward. St Helena Hospice make weekly Multidisciplinary Team visits onto the ward to support their end of life which has been well received. EPUT strive to ensure that everyone in their care has fair access

to care in the community. They have an outstanding CQC rating for end of life care. Nurses on their dementia units are very fairly included with St Helena Hospice surrounding their education programmes and ability to attend the education and training - Annette Knott, Manager of Tower Ward, Clacton Hospital is currently undertaking one of the nationally accredited courses that St Helena Hospice shared.

### **Colchester Hospital Palliative Care team**

Specialist palliative care needs are available for patients with complex needs. Additionally, End of Life Care Skills nurses generally see patients who are actively dying - within the last couple of weeks - taken from the Watchpoint system. For patients within the last twelve months who have been told in clinic that there is no further treatment will be undergone, a message is sent out to the GP so advance care planning can be discussed. The My Care Choices register is available whereby consultants input this information into the discharge summary to let the GP know. The Frailty Team actively look for patients with a frailty score above seven which will then trigger advanced care planning to be put in place for these patients.

The Palliative Team are working closely with the Frailty Team to ensure more advance care planning is put in place. There is active encouragement of the wards to have these conversations with patients, who may be being admitted on a regular basis, ie., with COPD. This has been very challenging since the Covid pandemic due to high turnover of staff, and junior staff who are finding it difficult having these conversations with patients. This is quite a challenge for the Palliative Team so they are grateful for their End of Life Care Skills nurses who can help. Videos have been created to support communications training for junior doctors to help them to feel comfortable to have those conversations with people.

Within the hospital setting, most wards will have a day room where difficult 'breaking the bad news' conversations can be had with patients/relatives but there is not yet any specific designated area for this. Hospital space is at a premium since the pandemic!

The hospital works very closely with hospices - particularly St Helena and Farleigh, but feels that they can do better, ie., signposting to mental health charities for those in crisis.

### Spotlight

Age Well East offer several services which provide emotional and social support. The emotional support services are free. Their Compassionate Companions volunteers offer support in the last months of life. These volunteers provide a bridge to the barrier for those who do not have the financial means.



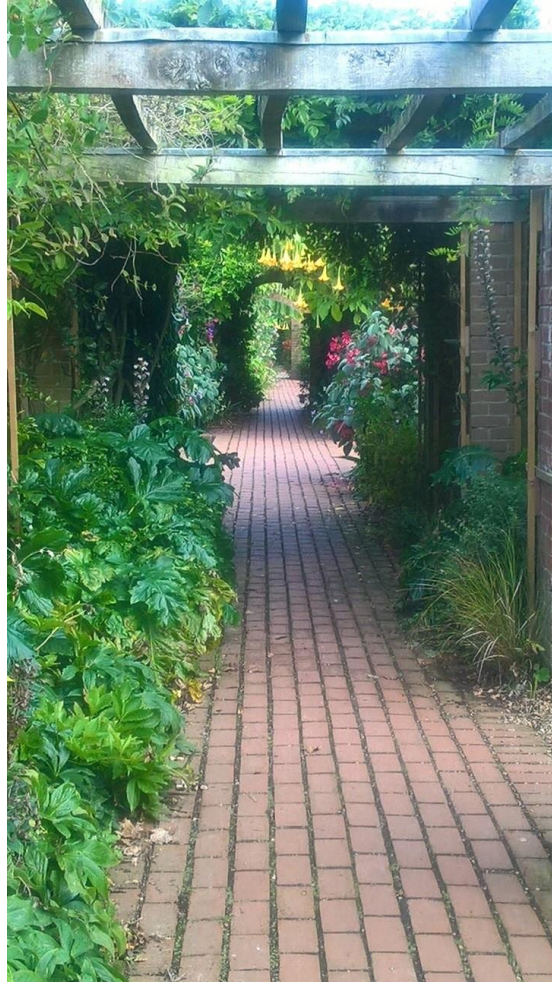
### Spotlight

Hunnaball Family Funeral Group have sites in both Colchester and Manningtree and have good connections within their community, resulting in recommendations from local care homes. Posters are used to advertise their Funeral Wishes service.



## Spotlight

Lexden Bereavement Support Group are located in the annexe to St Leonard's Church, Colchester. Though not a religious group, they welcome anyone whose loved one has died. The group, signposted by St Helena Hospice, is led by trained volunteers and offers six fortnightly sessions which includes discussions, video content and tea and cake on Thursday afternoons.





## Soul Midwives

The purpose of Soul Midwives is to lovingly ease the passage of the dying, to ensure that death is a dignified and peaceful experience. They offer a range of gentle therapies to soothe and reassure and are skilled advocates and advisors.

Often with a nursing and/or a healthcare background, they are non-denominational in their pastoral support, encouraging deep conversation, with love and dignity. Their work may begin from point of diagnosis and continue until the final day of life, with encouragement and support for living life fully, until the end. Soul Midwives are helping to transform the personal and collective experiences of dying and living within the community, by helping anyone facing the end of life to experience a tender, peaceful and conscious death.

Felicity Warner, founder and mother of the Soul Midwives movement, has been running her award winning courses for over 20 years. In 2017, Felicity was named End of Life Care Champion by the National Council for Palliative Care at the House of Lords. She was also named End of Life Doula of the Year in 2017 by the Good Funeral awards and was named Most Inspirational Women of the Year by the Daily Mail.

There is one Soul Midwife in the Colchester and one in Tendring.



**“The work of Felicity Warner and the Soul Midwives is absolutely crucial for those of us who believe that death is one of the most important moments of our life. By providing loving and gentle support, Felicity and the Soul Midwives support people to have the death that they want. What could be more important?”**



**- Jon Underwood  
Pioneer of the Death Café Movement**



## Recommendations

### 1 Communication

Improve communication and language around end of life. People do not know where to go to find information and more needs to be done to produce condition-specific and more generic information to ensure that individuals in their last year of life and their friends and families have the best and most accurate information available to them.

#### **Call to action:**

North East Essex Health and Wellbeing Alliance End of Life Working Group to review information and language used in leaflets, flyers, documentation and test them out with a focus group of members of the public.

#### **Education and Support - Each community is prepared to help**

The demand for end of life care is rising at a rate that professional palliative services alone cannot meet (Sue Ryder, 2021). Everybody has a role to play in supporting each other during times of health crisis and personal loss, but low confidence and a fear of making things worse, prevents people from helping when they can.

Through accessible education and support, people can quickly develop the knowledge, skills and confidence to support each other before and after end of life - even being able to start a conversation can make the biggest difference.

#### **Call to action:**

Develop and deliver an accessible community learning and awareness programme to demystify end of life care, and help people develop the knowledge, skills and confidence to help others experiencing death, dying and loss.

### 2 Forward Planning and Improving Death Literacy

Evidence suggests that not all My Care Choice Records are being completed by parts of the health care system, including GPs, care homes, hospital and hospice. There are a number of barriers and challenges which could explain this and further work needs to be done to address this issue.

Normalising the discussion about death and dying to enable stigma-free discussions to take place in advance of end of life by encouraging community assets to promote understanding of advance wishes and 'living wills', will writing, lasting power of attorney and funeral planning. We recognise the importance of planning but there are challenges with this - knowing when a plan can be enacted, differing experiences of process of planning, family living at a distance, treatment pathways being managed differently.

Raise awareness of and manage situations where the mental capacity of a loved one means they cannot make decisions without support.

**Call to action:**

A specific project is undertaken to explore how the health care system can be supported to increase the number of My Care Choices Records completed.

End of Life Awareness/Death Literacy Training to be rolled out to Community and Voluntary Sector Groups, Councillors, volunteers, and forums such as the Older People's Forum to remove some of the stigma around dying and encourage people to plan ahead. This has started through Compassionate Communities' objective to improve Death Literacy but needs to be extended much further.

### **3 Caring for carers - paid and informal**

Improve practical and emotional support to family carers. Where people are receiving end of life support from the hospice, carers are identified and supported but more needs to be done through GP services to identify and support carers for those who are not linked to the Hospice. Within the community there is a need for practical and emotional support to enable people to care for their loved ones and focus on their needs. A good model of this is Compassionate Companions, but it could be extended beyond those living alone with additional resourcing. There are many good carers support services in the community who are able to support people.

Recognise and plan for the intensity of relationships at the point of needing EOLC - paid carers and families can build very strong and trusted relationships over time, but this places high emotion and pressure on the staff and/or volunteers involved.

**Call to action:**

Businesses and statutory organisations to offer support to their employees who have had long term links with clients through and before end of life to recognise the impact of loss.

Involve and integrate carer support services within the planning and delivery of wraparound, holistic end of life care. Promote referral of carers to support groups at the time of diagnosis.

### **4 Developing networks of care**

Encouraging greater recognition from the VCSE sector of the role it plays at end of life - there is a focus on the role of clinical and specialist services at end of life, which contributes to groups reluctance to appreciate the role they can offer as wraparound support to people at end of life. This creates a tension between professional skills and community consideration that groups do not resolve easily. This affects the information they share with the public and undermines confidence in being able to effectively support people at this stage.

Inequalities feature a lot in this report, showing different outcomes as a result of different circumstances. Attention needs to be given to how these challenges can be overcome by working with communities and building networks and relationships which promote trust, confidence and accessibility.

Bringing domains together - work has emphasised the importance of connections with Stay Well and Age Well Domains and long-term health condition management and awareness.

Identify and map bereavement support available across North East Essex. There is a crossover with businesses (funeral directors) and faith groups.

**Calls to action:**

Build up a social model of care which complements the medical model of care and support individuals and families more holistically through end of life.

Explore means for building trust and relationships with all North East Essex communities to support tackling inequalities and promote understanding of and confidence in services.

Domain Leads Group to address impact of Community Asset Mapping on their domain and others as part of their agenda. Domain leads to identify crossovers as part of each deep dive.

End of Life Working Group to review options available for mapping end of life and bereavement support eg. the Essex Map and other available options, and consider investment in developing the resource and maintaining its integrity.