

Compassionate Companion Service

Evaluation

2024



The Peninsula Practice

A Collaboration of Compassion



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Summary

Integrated Care Boards (ICBs) are legally mandated to commission palliative care services (NHS England, 2022), ensuring high quality health care for their populations at End of Life (EoL). Without work by the ICB to support social cohesion and promote social capital, local populations suffer: patients, unpaid carers, and care professionals. We have one chance to get this right: endings matter for patients and those left behind (Kahneman et al., 1993).

With 9,612 emergency admissions in Suffolk for patients within the last 90 days of life in 2022/23 (SNEE IF, 2023), and this population representing more than 10% of emergency admissions (ibid.), and only set to increase, there is a necessity to support the complex and unique needs of people in the last year of life in a more effective and efficient way.

Anchor institutions such as acute hospitals, GP surgeries, place-based community health and wellbeing partnerships need robust and resilient links into communities at a neighbourhood level to support the wider determinants of health (Marmot, 2020, Marmot and Bell, 2012). The Compassionate Companion Service is a grass roots community-based initiative facilitated by NHS clinicians. Companions living and/or working in Ipswich and East Suffolk are matched with patients in their last year of life. They facilitate and document conversations around Advance plans (ReSPECT), resuscitation and care wishes, which are shared with relevant clinical teams for better proactive and anticipatory care. The Compassionate Companion Service works to improve outcomes, reduce inequalities, achieve value for money, and supports all non - and statutory stakeholders involved in EoL patient care via the NHS (NHS England, n.d.).

Compassionate companions optimise choice with future planning for patients at EoL thus increasing social capital through training and upskilling local communities in social palliative care.



A service delivered by the community, for the community.

Using calculations expanded upon within this report, we estimate a financial saving per patient supported by a companion of **£8,027** for reducing inappropriate hospital admission, **£326.80** per ReSPECT form facilitated by a Companion, and **£367** for avoidance of ambulance conveyance.

The service delivers key elements of the strategy set out by the National ‘must do’s’ (NHS England, 2022). and this report evidences how Companions play a key and skilful role supporting and working with all statutory organisations to achieve these ambitions.

The service has so far supported over 143 directly referred patients* (see below) with a 300% increase in referrals received between September - December 2023 (17) compared to the same period in 2022 (54)

*between April 2022 and Jan 2024

Comment from Dr Crockett (Service lead)

Over the 20 years I've worked as a GP I have concluded that it is not possible for health and social care teams alone to fully, wholesomely and holistically support a person in their last year of life. That is not to say that statutory workers do not give or care enough. On the contrary the moral injury is huge: I feel it regularly as a GP with such limited time to give to all those who need it, our social care colleagues and Integrated Neighbourhood Teams (INTs) who would love to offer more simply cannot in many situations due to increasing demands on the system. We rely on unpaid carers, families and loved ones and the enormous compassion inherent in our communities.

It was that recognition that ignited a small community project to equip the community with training, support and supervision to provide unhurried time, information and skill in enabling rather than disabling those individuals and their loved ones nearing the end of their lives.

“The Companion service is courageous, innovative and effective ”

Providing medical care for patients at EoL is estimated to cost the NHS at least £350m/year between 2021-2030 (Petersdorff et al., 2021).

This evaluation illustrates a potential average cost saving of around £10,000 per individual patient referred into the companion service compared to deceased patients who were not patients of the service. It has the capacity to reduce unwanted and avoidable hospital admissions, supporting all stakeholders in the integrated care teams and to improve GP capacity and access.

As part of a multi-disciplinary team (MDT), the service meets targets for improved quality, access and equitability of patient care at EoL as described by the Adult service specification for Specialist palliative and End of Life care services. (NHS England, 2022). It also delivers on elements of the SNEE (Suffolk and North East Essex) Joint Forward Plan goals for End of Life Care and the Ipswich and East Suffolk Alliance age well and die well domain plans (SNEE ICB, 2023).

SNEE joint forward plan die well domain

How will we (SNEE) make a difference?

The key priorities we will achieve by 2028 are as follows:

- The timely identification of the people who are approaching the end of their lives, communicating this with them and those who are important to them with sensitivity and honesty
- The eliciting, recording and supporting of people's preferences for care in the last phase of life, ensuring these are accessible to all parts of the health and social care system
- People at the end of life are treated equitably as individuals, with dignity, compassion, and empathy, controlling symptoms 24 hours a day

Overall Outcome:

Giving individuals nearing the end of life choice around their care

Overall Commitment:

We will enable people and their families to have high quality care and support from all health and care professionals involved at the end of their life



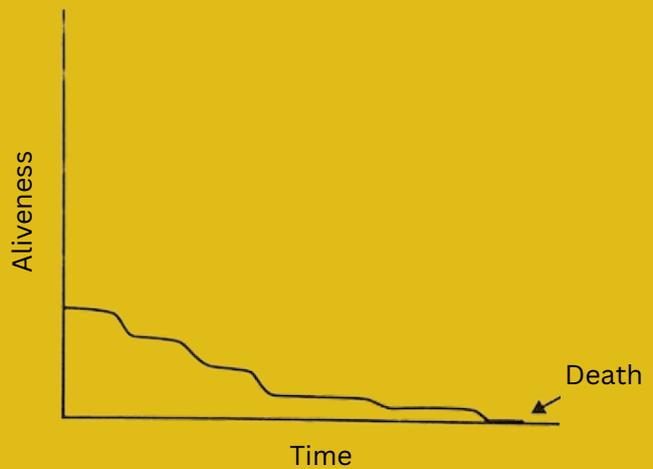
Many people are not told they are likely to be in their last year of life as we try to fix and hope that things will get better.

Yet there are obvious signs that a person is in their palliative phase. Challenges of time, competence and courage are key reasons that such conversations are avoided. Referring into the companion service mitigates against this.

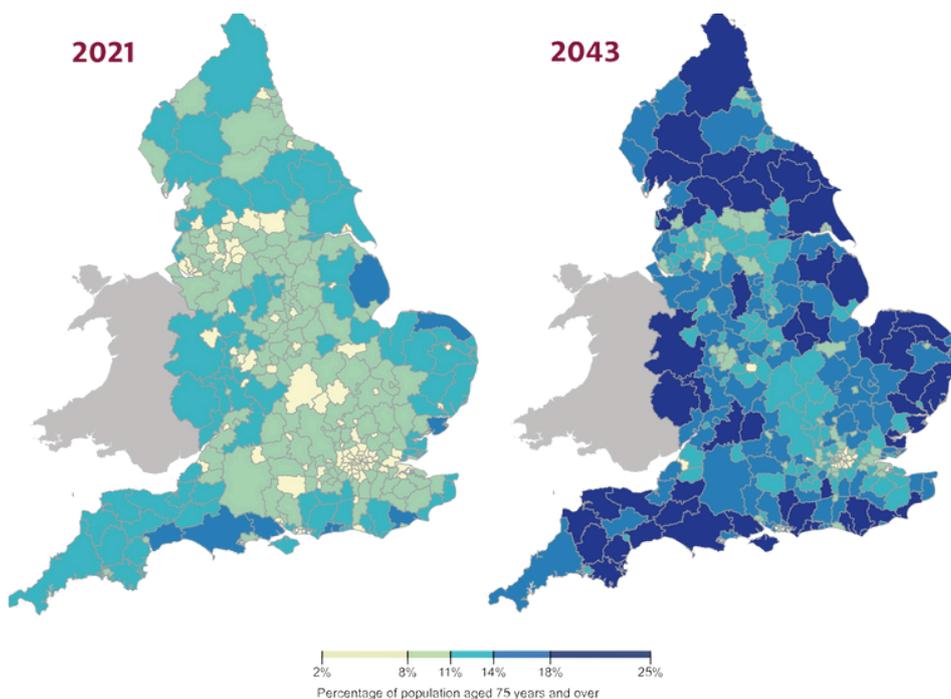
Medicalising the last year of life

The progress of death is medicalised to such a degree that we can't really tell when meaningful life has ended.

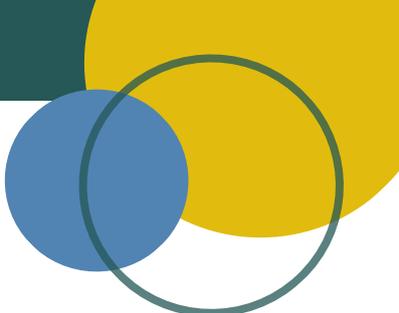
We can be kept alive almost indefinitely with a variety of machines and medicines. "We reduce the blood pressure here, beat back the osteoporosis there, control this disease, track that one, replace the failed joint, valve, piston, watch the central processing unit gradually give out (Atul Gwande, Being Mortal) .



The curve of life becomes a long, slow fade.



Map of England showing the projected rise in the percentage of the population aged 75 years and over (CMO Annual report 2023)



Introduction

In 2021, there were 8,399 deaths in Suffolk (Office for Health Improvement and Disparities, 2023), and 7,839 deaths registered in 2019 (ONS, 2023), (the last year of data before the emergence of Covid-19 in the UK). As noted in the Chief Medical Officer's annual report 2023 (Whitty, 2023), palliative care is not equally distributed, and patients with non-cancer terminal diagnoses are less likely to benefit from palliative care.

In a 2015 survey of bereaved people, 60.4% of 20,922 respondents said that they had not had discussions with their deceased loved one about their Preferred Place of Death (PPD). Of those who had discussed where they would prefer to die, respondents reported that 81.1% (count: 6,075) of deceased patients expressed a wish to die at home, yet only 41.1% (3,672) were documented for healthcare staff to be aware (ONS, 2015). Patients who died at home were more likely to have shared their preference for a home death with their loved ones than those who died in a hospital.

“families should have conversations with older relatives about their health choices, wishes and health interventions in the event of a medical emergency and other serious illness. We need to have more realistic conversations and prioritise people’s quality of life. Most older people do want to have these conversations, but possibly also shy away from them. Of course, it can be difficult to have these conversations within families, and denial is a very powerful factor.” (Whitty, 2023)

The Companion service supports people who have been identified as End of Life by allocating volunteers who have attended a 2-day training programme. Harnessing the skills of compassion and empathy claimable in us all, compassionate companion volunteers donate their time, offer information, support, and document a patient's advance plan; their health understanding, and life and death choices as they approach the end. They listen to and enable what matters to the individual rather than the clinical question of ‘what is the matter with them’.

Working with colleagues in the acute trust, there is a burning platform of need to have more proactive and honest conversations with people before they arrive at the emergency department.

The age demographic of the UK is changing; the English region with the largest population increase was the East of England, which grew by around 8.3% or 488,000 more residents. This ageing population requires greater and more complex health and social care.

Everyone has the right to be involved in their future care and make choices including around their dying. Yet 70% of us will have someone else make decisions on our behalf in the last months of our life.

With the reduced number of healthcare professionals per patient in coastal communities (Whitty, 2021), it is particularly important to improve community mobilisation and build local volunteer capacity to support End of Life care.

The Importance of Advance Planning and how a Companion can help

63% of us want to die at home

23.5% of us die at home

28% of us want to die in a hospice

5.7% of us die in a hospice

8% of us want to die in a hospital

46.9% of us die in a hospital

1% of us want to die in a Care Home

21.8% of us die in a Care Home

(Petersdorff et al., modelling demand and costs for palliative care services in England, 2021),



“

I would like to say a huge thank you to the compassionate companions service for undoubtedly making such a meaningful difference to our local population living with frailty and life limiting conditions, who now have the chance to have their voice heard and have discussions as to what truly matters to them with enthusiastic, empathetic engaged individuals who put the person at the centre of care.

It is so important for those most vulnerable living with advancing frailty to ensure their wishes are respected and prevent unnecessary trips to the hospital and unwanted investigations in most cases this group of people are in the last year of their life and their needs and wishes change with time. Having advance care planning discussions about what matters to them most and being able to ensure all the healthcare professionals they have contact with know this stops multiple trips to the hospital or GP surgery and allows them to spend the time they have left knowing they have had the chance to talk things through with someone.

The referral process has been excellent and we can see that clearly it is making a difference, it is obvious to all who work with individuals in the later years of life how important and vital these discussions are.

Having a service that is impartial and manned with an army of wonderful well-trained volunteers allows time to get it right. It's not about stopping hospital admissions or reducing bed days it is about having the wishes of our frail population heard loud and clear. We have seen how it can reduce unnecessary and painful tiresome admissions in our very frail in the care homes and how often they leave hospital in a worse state than when they came in. I truly believe this service makes a difference to scores of people and I only hope it will continue and go from strength to strength in the future. Thank you so much again to the compassionate companion team for all they do and I hope we can keep these conversations going.

Dr Dan Coates
Consultant Physician, Older People's Medicine
Clinical Lead, Ipswich, Older People's Medicine
Associate Medical Director Patient Safety

Service impact – Cost Savings

90% of people spend time in hospital in their last year of life (Public Health England, 2017). Of those, in the last year of life, patients spend on average 23 days as an inpatient (Luta et al., 2020).

The Compassionate Companion Service is an NHS service which requires funding. Here we illustrate how the service has cost effective potential and opportunities to develop further cost-savings in the future.

Reducing inappropriate hospital admissions:

Impact of a completed Advance Plan (ReSPECT form) has been shown to reduce inappropriate hospital admissions, thus potentially saving at least **£8,027** (Jones et al., 2022) for a single admission of a week or more.

GP Access and Capacity:

Companions facilitate advance plan completion by discussing and documenting conversations with patients referred into the service. saving at least **£326.80** for GP access and capacity per advance plan facilitated by a companion.

Ambulance conveyance:

Avoiding an unwanted and/or inappropriate hospital admission saves ambulance conveyance costs of **£367** for attendance and transport for treatment (Jones et al., 2022).

Reducing inappropriate hospital admissions

For patients who wish to die at home, documenting this preference in their ReSPECT form enables their healthcare team to reduce the likelihood of the patient being admitted to hospital in an unplanned, emergency admission. **This translates into substantial cost avoidance for expensive inappropriate and unwanted treatments and inpatient stays. The companion contribution has the potential to save £8,027 + conveyance costs for a single patient.**

The purpose of the Compassionate Companion Service is not to enforce a death at home policy. The aim is to ensure patients are included in conversations around their care, that their wishes are documented, and Preferred Place of Care and Death (PPC/PPD) achieved.

70%

70% of people will have end of life decisions made on their behalf because advance planning conversations have not been had or shared with the right professionals

81%

81.1% of people state their PPD as home (ONS, 2015), yet in 2022 in the SNEE ICB boundary, 49.9% of decedents died at home of whom 22.9% were in a care home (OHID, 2023).

In the last year of life, healthcare costs reach £8,089.80 and £6,898.40 for men and women, respectively (Luta et al., 2020). A further study found secondary care costs to reach £10,134 in the last year of life (Diernberger et al., 2021). Unit costs in the last 12 months of life were estimated at £7,979 per patient in 2022 (Jones et al., 2022). In the final 90 days of life, emergency in-patient admission costs reach £3,465 on average per person (Georghiou and Bardsley, 2014).

Cost of hospital admissions and potential savings from companion service

90%

will have a hospital admission in their last year of life*

25%

will have 3 or more emergency admissions in their last year of life***

15%

higher likelihood of admission at end of life amongst ethnic minorities**

10%

will have 3 or more emergency admissions in the last 90 days***

14%

more likely to die in hospital if in an ethnic minority group**

10.5 days

is the average length of stay for End of life patients - double that for all emergency admissions and not related to delays in discharge**

60%

will have an emergency admission in their last 90 days of life**

References:

*Public Health England, 2017

**SNEE IF emergency admissions 2023

***Nuffield <https://www.nuffieldtrust.org.uk/resource/end-of-life-care>

These figures demonstrate the financial costs placed on the NHS from the current system of EoL care, and the Compassionate Companion Service has identified opportunities to reduce these costs through reduced unplanned emergency admissions by facilitating appropriate, patient-centred decisions. The term inappropriate admissions is used in this report to describe hospital admissions which are unplanned, medically avoidable, and/or with foresight, the patient would not have wanted.

Impact of Hospital Admission on Older people

- 50% of patients experience functional decline between admission and discharge
- 2.5 to 5 % loss in core strength after 24 hours in hospital

- 48% of patients over 85 years admitted to hospital die within a year
- Up to 50% of older people become incontinent within 48hrs of admission to hospital

- 10 days in hospital for patients over 80, ages their muscles 10 years (Kortebein et al., 2008)
- 17% of older medical patients who were walking independently 2 weeks prior to admission needed help to walk

6 months after discharge from hospital admission, older people:

- 43% needed continuing help with medications
- 24% were still unable to walk a quarter of a mile
- 45% were still unable to drive.

Dr Dan Coates, Ipswich Hospital Trust

Using outcome measures of similar services in other locations, we can apply their findings to estimate the cost savings from reduced inappropriate hospital admissions.

An Australian study providing community support to people identified as EoL saw a statistically significant reduction in the number of inpatient days per month and hospital admissions (Aoun et al., 2023).

A study in Frome (Abel et al., 2018) supported patients with care planning within a compassionate communities model if they matched a selection of criteria (including but not confined to EoL. They calculated a 14% decrease in the number of unplanned admissions compared to the base number, whilst the control population had an increase in unplanned admissions of 28.5%.

Furthermore, when a person is admitted to hospital in their last 90 days, due to rapid de-conditioning as a direct result of the admission alone, there is a higher likelihood that they will not be discharged to the place they were admitted from due to higher needs of care thus further adding demands and expense on the system.



GP Access and Capacity

The ReSPECT form is the locally agreed format for documentation of advance plans. This involves sensitive conversations requiring confidence and competence over several face to face meetings in most cases. Primary Care colleagues with 10 minute consultation time allocation suffer grave moral injury in recognising the need for these, yet capacity constraints make it impossible except in crises situations in most cases. The reality is that advance plans are often left too late to activate proactive anticipatory care hence increasing the numbers of patients avoidably going and, often, dying in hospital. Nor do GPs have time to discuss and document non - medical care wishes.

Reflections of a GP on a 20 minute home visit to a patient in last weeks of life

Before my visit I was ready to discuss palliative and possible EOL care, however this patient was not ready yet for this kind of conversation. I recognized they need more time to accept the bad news. She doesn't have full insight of disease progression and affect on further treatment, or she just wasn't able to accept the evidence. I saw strong personality ready to fight disease sitting in front of me although expertise (oncology specialist) giving poor prognosis. Sometimes people need more time and multiple consultations to start considering comfort approach. This was concerning as in case of sudden and further deterioration a patient with advanced metastatic disease and poor prognosis can be apparently considered for full resuscitation and unwanted admission. We knew she wanted to die at home. This wouldn't be fair to patient, family or paramedics/medics who provide treatment. However I was not able to involve the patient this time in discussion about DNACPR/ReSPECT form.

As a minimum, the average time required for a GP to have such conversations and complete the ReSPECT form alone when someone is near to death is 1.4 hours:

- 1 x home visit = 60mins (inc travel time, noting that the majority of severely frail/EoL patients are housebound),
- 2 x telephone consultation = 25mins.

Using 2022 unit costs (Jones et al., 2022), this is a total cost of £371.00, on average.

With the involvement of the volunteer, the time required of the GP decreased to 1 x telephone consultation, totalling a cost of £44.20.

For completion of the ReSPECT form alone, a saving of at least £326.80 per form when facilitated by a Companion in terms of saved GP time

With the ever-increasing age demographic of our area equating to a growth in complex care required for our ageing population, even the GP Recovery Plan (NHS England, 2023a) will face significant challenges without investment in social capital and community empowerment.

The service:

What Does a Companion do?

“The compassionate companion scheme helped my late wife Rachael to live her final months in the way that she wanted to. Knowing that her wishes and treatment preferences would be respected, therefore enabling her to enjoy her family and friends until her last moments without the fear of being hospitalised away from her home and family.

Seeing the hope and peace this gave her prompted me to join as a companion to enable others to have similar say over how they live their final days. Which in turn gives me a new purpose in life.”

Testimonial from a bereaved husband, now current companion



Since the conception of the Compassionate Companion service in 2019 (during which covid induced a two-year pause), 143 referrals have been received to date (January 2024), all of whom are/ have been supported by the service with their choices at End of Life.

ARC of Dying

A

Advance plans – ReSPECT form – companions support the documentation of advance plans during conversations with the patient to state their priorities at End of Life. It is then passed to the registered GP practice who reviews with a summarising conversation (manageable in 1 telephone consultation in most cases) and signs off as senior responsible clinician. It includes the patient’s resuscitation status and treatment preferences. A film to support companions using the ReSPECT form has been made. https://www.youtube.com/watch?v=1juKpvx_IcE

R

Resuscitation form – prior to the ReSPECT form (introduced in 2023), the resuscitation form indicated to other healthcare professionals the Resuscitation status of an individual. Now incorporated into ReSPECT forms it is still an essential component requiring an often sensitive discussion over several visits. Methods including the **Resuscitation film** are used with patients and families to explore resuscitation more fully. <https://www.youtube.com/watch?v=rJlpbVp1l8>

C

Care wishes – rarely completed by healthcare professionals, this document includes more holistic considerations for the patient to discuss and document before/as they reach EoL. This is an essential component and includes digital literacy awareness; funeral wishes; faith requests; enabling patients to die knowing things are in place for their grieving loved ones.

How the Companion Service is Delivered

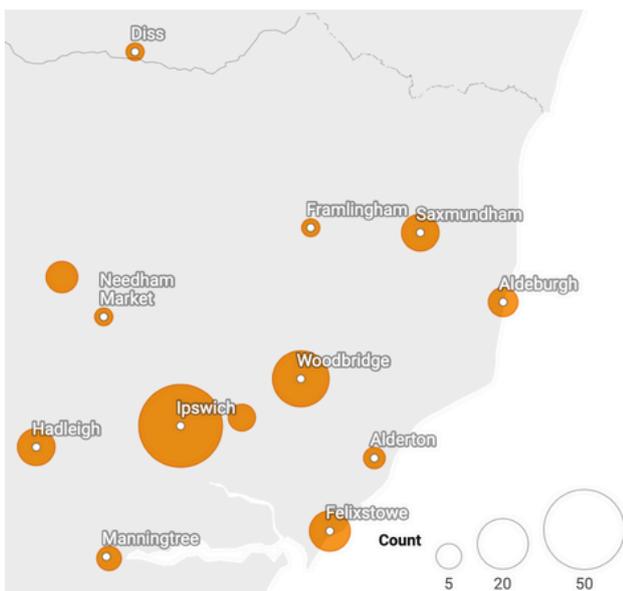


Patient inclusion

Criteria for patient referral to the service is simple: if a patient is registered with a GP in Ipswich and East Suffolk and identified as likely to be in their last year of life and would benefit from support for EoL discussions and decisions, they are offered compassionate companion support. With consent, or that of an attorney, they are referred into the service. Anyone at all including the patient themselves can make the referral.

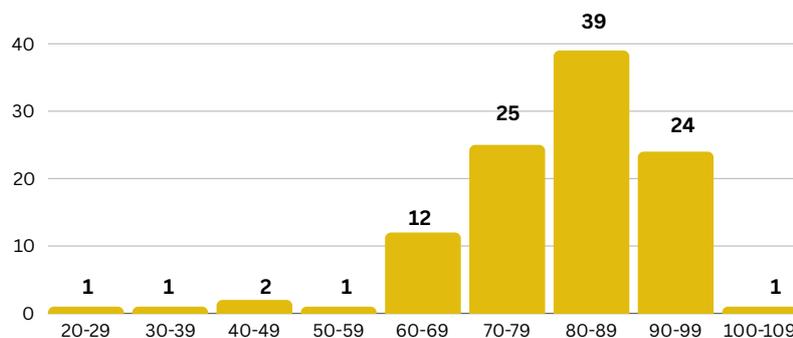
Dementia, cancer and frailty are the top three conditions mentioned on referral forms with Motor Neurone Disease, Parkinsons disease, respiratory heart and renal failure common conditions.

Referral forms are on medical systems for primary care (dxs), community (Community care coordination centre) and acute trust referral platforms (evolve). They are also available for self referral via our website www.compassionatecompanions.uk



Home-towns of 143 patients referred to Compassionate Companion Service. Larger pin size correlates with greater patient numbers referred from that area. (created with DataWrapper)

Patient ages (as of 15/1/2024)



Graph of number of patients referred to Compassionate Companion Service by age group.

The majority of patients are aged 70+, as shown above. As part of the proactive care model (Eastern AHSN, 2023) for people living with more than one long-term condition (including frailty), the Compassionate Companion Service supports all six components of the model:

1. Case Identification

Any person identified as being in their last year of life or living with severe frailty can be referred to the service with their consent, or their advocates if there is lack of capacity to consent. Additionally, through a positive and innovative relationship with the hospital, patients who are identified as living with frailty or approaching EoL are offered a Companion to complete the ARC forms. The clinical leads of the service validate the referral and the patient's eligibility for the Compassionate Companion Service.

2. Matching companions/ holistic care

The clinical leads contact the patient following referral to understand their needs and explain the service. This information, with the patient's permission, is shared to their Companion to ensure their needs are prioritised and met. One of the clinical lead team attends the initial introductory home visit between a new matched patient and their volunteer companion – this allows for a risk-assessment for all involved. Companions are enabled to signpost patients to other NHS or charitable services (including Meals on Wheels, or RNIB), allowing the patient to access all support for which they are eligible.

3. Personalised care and support planning

Through their relationship with the Companion, the patient receives personalised and targeted care which is communicated to their GP. Support planning is included in the completion of the ARC process (page 12)

4. Multi-disciplinary working

The Compassionate Companion Service clinical leads, in coordination with the patient's Companion, medical teams and care team (if patient is living in a care/nursing home) work together to support the patient and the identification of the patient's needs. The ReSPECT form is saved to the patient's medical record to ensure it is accessible when healthcare professionals require.

5. Coordinated care

Once matched, companion support helps coordinate patient care as well as signposting. The registered practice is made aware that the patient has a companion. The clinical leads of the Compassionate Companion Service ensure that the patients are eligible for the service. The volunteers are fully trained and have DBS checks, confidentiality and safeguarding training. They allocate support and monitor the service.

6. Interventions & Support

Facilitating and documenting advance care plans and care wishes enables proactive interventions and support to be put in place including signposting and companionship.

Volunteer Role

To date* there are 41 trained and active companions of which 18 are volunteers and 23 champions.

The Compassionate Companion Service recruits volunteers within local communities. Volunteers provide practical, emotional and social support within the context of EoL- with each contact varying according to the individual need of the patient. Two key aspects of the volunteer role include facilitating the completion of ARC documents and planning for future care.

Volunteers are asked to commit to offer at least an hour per week and complete an application for the training, explaining their motivations for being a Companion, and any experience they have with dying and bereavement. They must then attend a 2 day in-person training programme delivered by Dr Crockett, the clinical team and two experienced companions which includes safeguarding training, active listening, the role of the companion, and learning from experienced Companions. A further half day is spent online to complete mandatory safeguarding and confidentiality training.

Companion Volunteers and Companion Champions

There are two types of companions: **Volunteers** and **Champions**.

Volunteers

Companion volunteers living within their local communities offer their own time to support patients. Ongoing supervision is provided after the first introductory visit with a service clinician by fortnightly peer group sessions, regular surveys, f2f social meetings and whatsapp group for the whole team. Clear guidelines and governance are an essential component of the service.

Champions

Companion Champions are statutory workers in the health, care, and social service sectors who want to upskill their End of Life training to utilise within their post and during their working hours. Common professions we see among the Champions are care home staff, PCN patient coordinators, and Integrated Neighbourhood Team staff (therapies/nursing).

There is no hierarchy between the Companion volunteers and Champions; humanity and compassion are all the qualifications required: both groups attend the same training sessions. Volunteers receive an extra half day of training to include safeguarding, confidentiality, a Q&A session and completion of DBS documentation. Companion Champions have such governance managed within their employing organisations.

*as at 25/1/24



**Daughter of a patient
- feedback to their
Companion**

“Just a quick email to thank you for your help and empathy towards our situation with mum. As you could tell it was incredibly difficult for my dad to talk about certain things but having you explain definitely helped us as a family to start to have these conversations. Although in our case it was a bit late for mum to really voice her opinion we know as a family what she would like if possible and personally I found it easier to get dad to open up a bit so thank you and I hope you and your organisation will carry on your great work.”



Training and Support

The original training for the pilot project in 2018 was delivered by Living Well Dying Well Ltd (not for profit company). It consisted of the first 5 days of a longer programme provided for end of life doulas and was designed specifically for our Compassionate Companion project. Realising cost pressures and working together with End of life Doula UK (community interest company) the training transitioned in 2022 to a train-the-trainer model over 2 subsequent programmes. In 2023 with the introduction of the ReSPECT form, challenges of GP access and capacity across the system including increased numbers of unwanted and avoidable hospital admissions, the training programme was completely redesigned.

There was a need for competence training for volunteers in all aspects of non medical palliative care and the ARC of dying well approach was adopted. Training is now delivered by a combination of lead GP (Dr Crockett), clinical lead and assistant (Kate Barber and Bill Thompson) and keeps the essential elements of grief and care wishes delivered by current companions. The golden thread throughout the training is one of compassion and includes self-care awareness for the companions.

With increased demand for training combined with the pressures of statutory staff being able to get cover, we reduced training from 3 days to 2 days for statutory champions which has seen an increase in numbers applying.

Quotes from Companion Champion feedback:

“this training enabled me to be more confident starting conversations with patients”.

“ReSPECT form completion was more in depth to other training received.”

Governance

Clinical governance via the service leads is imperative due to the integrative nature of the service and the vulnerability of the population served.

Governance of volunteers comes with risk which is quite different to that taken on by employing organisations.

Employees are duty bound to obey policies and protocols whilst volunteers have fewer conditions. Confidentiality and safeguarding training are emphasised heavily and, whilst companions hold no responsibility for patient care, a clear pathway for companions to signpost is provided thus avoiding confusion of role. Having a well led and responsive team is imperative to guide, advise and on occasions take authoritative decisions on certain aspects of service delivery.

Well led, Responsive and Safe:

Once trained and matched with a patient the support and supervision continues with fortnightly peer group meetings with the clinical team where all companions are encouraged to attend. This is a rich forum of support and shared learning and identifies needs of individual companions.

All companions are added to the Compassionate Companion WhatsApp group which allows ongoing contact and support between companions and the clinical leads – all members of the team are encouraged to share anonymised motivational experiences, seek advice, or share any information that they deem useful to the service.

Record of contact – without a means to record contacts in medical records we devised a way to ascertain the nature and themes of the contact as well as number of contacts taken to complete ARC documentation - companions currently complete an anonymised simple online survey (survey monkey) with each interaction.



Companion Service in Action

"I was delighted that it resulted in completing the Respect form for both mum and dad and a discussion with the GP. Something I don't think would have happened [without] the CC intervention."

"We discussed progress on getting counselling and connecting her to talking books but both of these were a) slow. B) encountering technical difficulties. [I] asked whether she would be happy if she tried to look into arranging more people to visit her (befriending schemes etc). She was happy with this."

"Great to help the next generation of GPs."

"Positive input & encouragement to client to open up & express fears, doubts, plans, dreams, hopes and so on."

The ARC of Dying Well

Resuscitation

Advance
A planning

Care
wishes

"I did the ReSPECT form with her and left it at the practice for the GP to complete."

"Client and wife said they appreciated time I gave them to explain things - and they feel GP would not have this time to give."

"I left two letters (samples) for J which we had discussed at my last visit & which I wrote out for his children from him, expressing what J had told me he wanted to say to his children before his imminent death."

"I think he has come to depend on my weekly visits. They remind him of a wider world."

"A clear conversation was done about how the patient want to be treated in an emergency and if his condition deteriorates further."

"She seems genuinely and deeply to value my support over the last [months]"

"It was difficult to initiate the conversation as family was already distressed but as I explained the different aspect of RESPECT form which was just not about what should be done when the patient's heart stops but also about his wishes on what should be done before that, they felt at ease."

"I was able to help her explore all her fears, doubts and worries in a calm and compassionate manner."

"She is mentally frail so you feel you are skating on thin ice. But skating is fine!"

"I check how she is feeling physically and mentally."

"Recognising that she was not in the right place mentally for this discussion and knowing when not to push the subject."

"I feel my role as a companion can be a significant help and it is not always about the 'doing' aspect of compassion."



"Client and wife said they appreciated time I gave them to explain things - and they feel GP would not have this time to give."

Qualitative Service Impact – 6 Ambitions National Framework

The Compassionate companion service sits within the wider national and regional context of End of Life care. The Ambitions for Palliative and End of Life Care (National Palliative and End of Life Care Partnership, 2021) This is an integral framework and assessment mechanism to ensure the service meets high levels of care. These will be referred to regularly in the following sections.

01 Each person is seen as an individual

02 Each person gets fair access to care

03 Maximising comfort and wellbeing

04 Care is coordinated

05 All staff are prepared to care

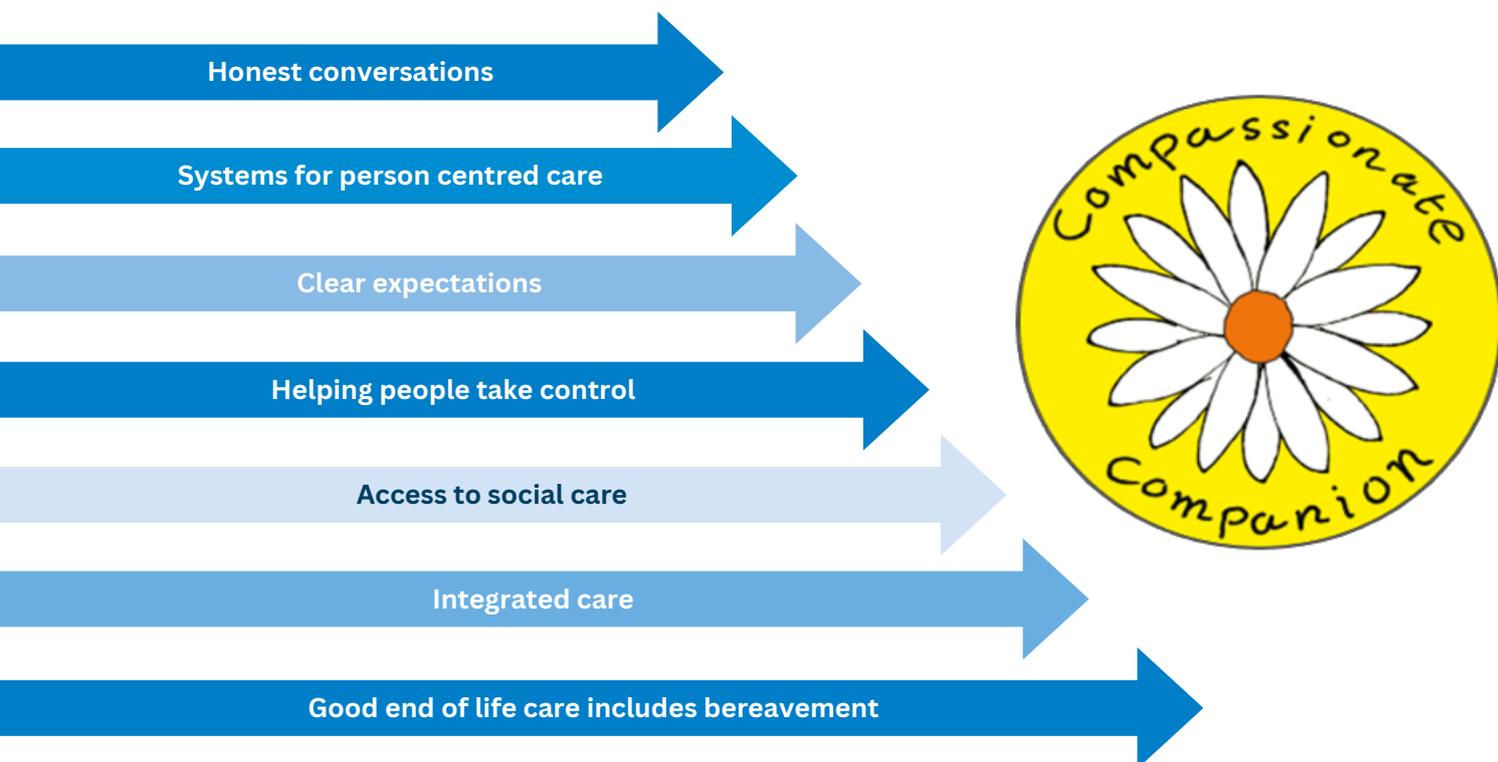
06 Each community is prepared to help



The Compassionate Companion Service fulfills all six 'must do' NHSE Ambitions for Palliative and End of Life Care

01

Each person is seen as an individual



How our service achieves ambition 1:

End of Life care is **person-centred**, and the Compassionate Companion Service provides support that is tailored to each patient in the service, as recommended by the World Health Organisation (WHO, 2020).

Companions offer the opportunity for **honest and well-informed conversations** about dying, death and bereavement.

The aims of the service are to ensure that people approaching EoL **know what to expect** and have their wishes understood by all who are involved in their care, and their wishes are recorded. This includes PPC, PPD, resuscitation wishes and more holistic needs, including funeral preferences/wills/digital legacies etc.

Companions are in ideal position to support **access to social care** identifying needs based social and other non medical care at the individual level. 23% of recorded volunteer contacts have involved signposting patients to wider community support services, including social prescribers, the Royal National Institute of Blind People, Meals on Wheels, and others.

As summarised in the Better Endings report (NIHR, 2015), PPD is not always achieved, with variation occurring due to diagnosed condition, age and care availability. This service is developing close connections with frailty specialists, heart failure, COPD and renal teams as well as out of hours and medical examiner teams to increase the proportion of people identified and being able to die in their preferred place and reduce the barriers preventing this from happening.

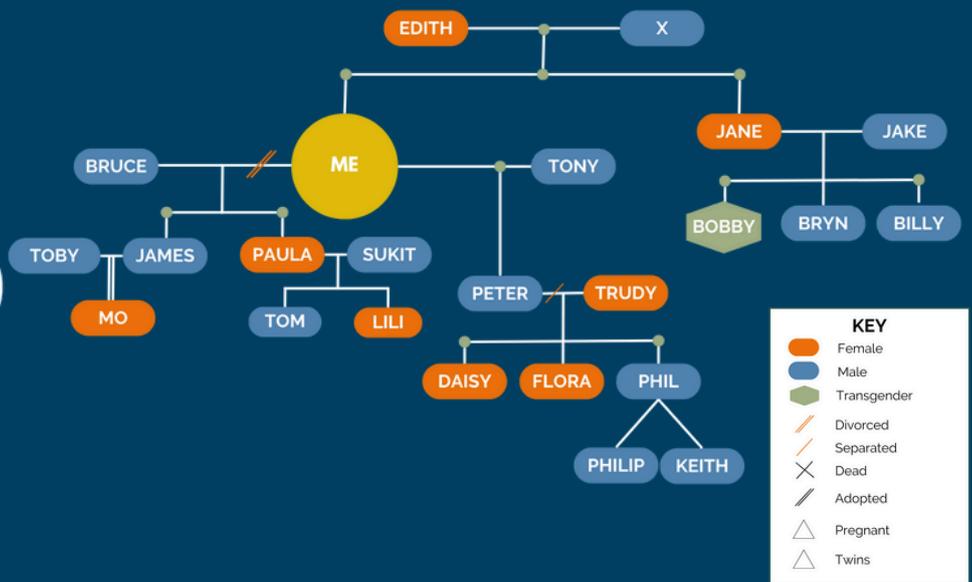
Companion care for the individual includes understanding the need to support their unique set of relationships with family, friends, carers, other loved ones and their community, including preparing for loss, grief and **bereavement**. Tools such as circles of support are facilitated by companions as well as genograms to illustrate those close to the individual at End of Life.

Patient empowerment, enabling patients to have **greater control** over treatment affecting their health is achieved through supporting patients to consider and document their treatment wishes as they reach End of Life (Nutbeam and Muscat, 2021). Each document must be signed off by a healthcare professional involved in the patient's care, further cementing the approach of **integrated care** for each patient from their individual perspective.

Circle of support at end of life



Genogram



Person-centred care - companions enable patients to consider themselves in the context of professional and personal relationships

02 Each person gets fair access to care

Using existing data

Generating new data

Community partnerships

Unwavering commitment

Person centred outcome measurement

Population based needs assessment



“The quality of end of life care is poorer and harder to access for people who live in very rural or other isolated areas. There remain unacceptable inequities and inequalities in access to palliative and end of life care particularly for those with learning disabilities, dementia and non-malignant long term conditions.” (National Palliative and End of Life Care Partnership, 2021)

How our service achieves ambition 2:

The quote above from the National Ambitions framework explicitly states the inequitable state of the current provision of EoL care. Eligibility for inclusion in the Compassionate Companion Service is all inclusive for any person identified as being in their last year of life.

Emergency admission data alone evidences the disparity between likelihood of admission and dying in hospital among those in ethnic minority groups (page 9). **Using existing data** including Public Health Medicine data informs us with the hard facts that deprivation equates to less equitable outcomes. This service complements the work being done to close the equity gap by supporting **community partnerships**.

Identification of patients in their last year of life is a national challenge and patients with palliative heart failure, end stage renal failure, dementia, children and COPD etc are often denied their right to know they are dying. Conditions with defined trajectories such as cancer constitutes about half of patients referred into the service. We will continue to **measure person centred outcomes** and have started conversations with the Medical Examiner service to assist us with feedback from the bereaved after death to further evaluate and **generate new data** for the service’s success in ensuring each person gets access to care.

Furthermore, the companion service is working with frailty teams in the acute trust to identify patients with frailty who are in their palliative phase rather than having any specific disease category thus, the service is working to improve capturing non-malignant illnesses and working with maximising autonomy of choice, comfort and wellbeing.

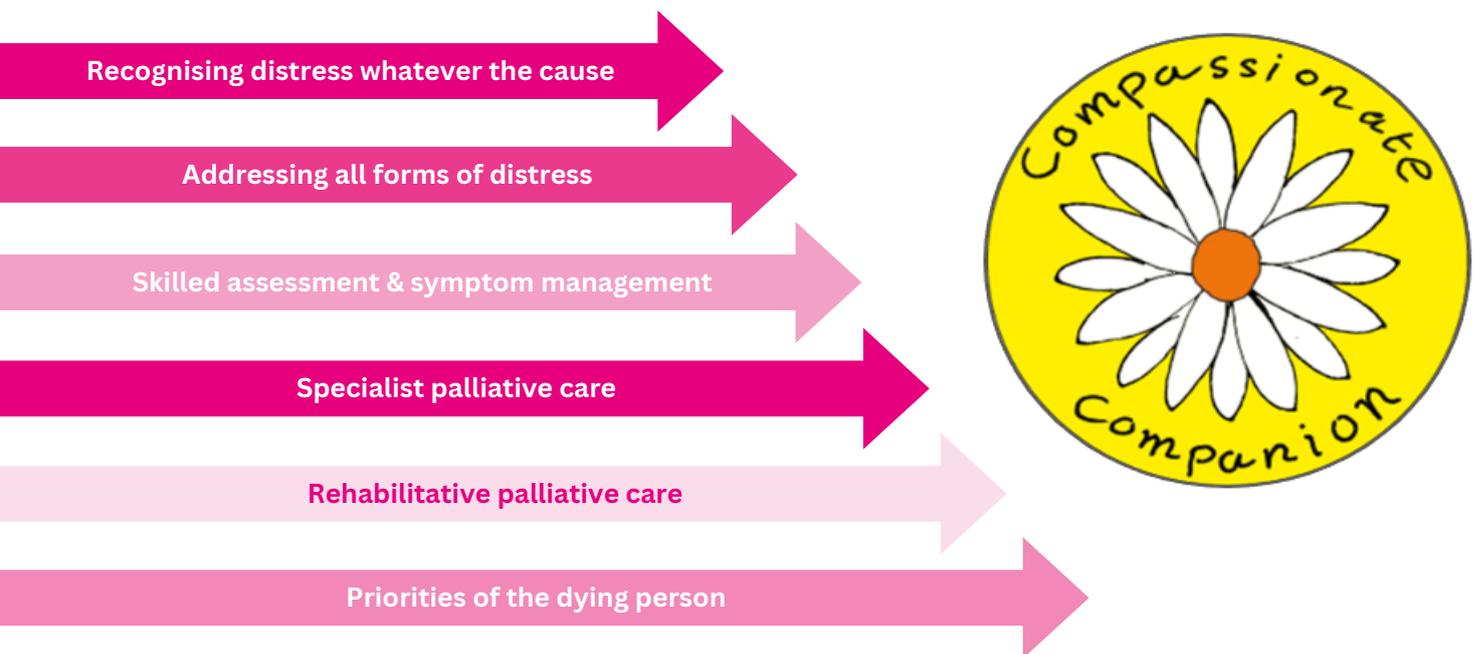
People approaching the end of their lives need medical care on average for only approximately 5% of the time. (Sallnow et al., 2022) This means the overwhelming amount of time they spend living with their life limiting conditions is without healthcare.

Professionals have limited capacity in managing the emotional and spiritual wellbeing of individuals and companions provide non-medical compassionate care in all its forms.



03

Maximising comfort and wellbeing



How our service achieves ambition 3:

Companions use time, compassion and empathy to help patients understand their worst fears, to alert these on the necessary documents thereby enabling all teams to anticipate and proactively manage. By documenting such information people can **recognise potential sources of distress** that might not be obvious and mitigate to relieve them.

All forms of distress including spiritual distress can often go neglected due to a multitude of reasons not least lack of time and confidence. Companions have the training and capacity to identify and support emotional, psychological, social and spiritual concerns.

Physical comfort, pain and symptoms are best controlled proactively. Companions can alert teams sooner than later before relying on hospice/ INT/ GP to identify such needs often when crisis has already been reached. In this way companions can alert teams for **skilled assessments avoiding delays in symptom management**.

Companions are a conduit for signposting and accessing vital services including **specialist palliative care** via the hospice hub, they are equipped with necessary contact numbers to alert the One call number as well as to enable logistics teams for practical equipment and support.

Rehabilitative palliative care

Autonomy is a cornerstone for companion care, recognising that despite being in their last year of life people can still feel well, stay independent and prevent elements of frailty. Companions support **patients achieve their personal goals**, to make decisions, build and maintain relationships, and manage their affairs.

Compassionate care is the ethos of companion care - a key priority of the Leadership Alliance for the Care of Dying People (2014). Compassion needs time and companion volunteers have this sought after commodity and as such are key enablers within the integrated care system to **prioritise care for the dying person**.

Feedback from a relative of a referred patient

“I wanted to say a massive thank you for all your support, we had some very tricky times and I was having to fight for things that were incredibly painful, but your support and guidance was an amazing help, and of course your ability to get things sorted was invaluable.

You will always be in our hearts as the lady that helped dad have a peaceful end to his life, thank you so much”

04

Care is coordinated

Shared records

Clear roles and responsibilities

A system-wide response

Everyone matters

Continuity in partnership



How our service achieves ambition 4:

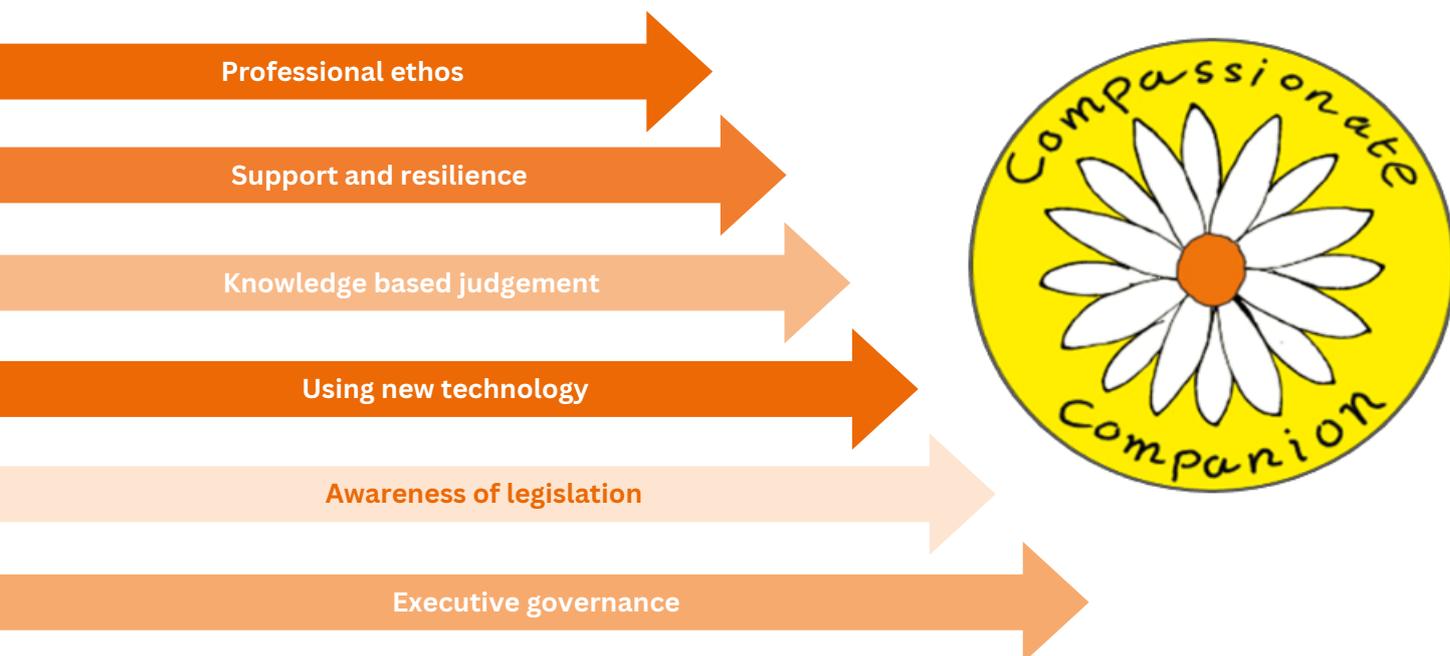
Companions can support the coordination of care for those patients who require it. Training equips companions with an awareness of services available and how to signpost effectively for joined up care. A common theme from patients and families is about fragmented care and uncertainty of who to go to and what is available. The training equips companions with all necessary contacts including local social prescribers and essential phone numbers to signpost for all concerns. Companions have **clear roles** and are trained not to take any responsibility and to hand over any issues (page 13).

This ambition describes how a **system wide response** and **working in partnerships** are essential to be able to use coordinated services and participate in active partnerships between NHS, social care and the voluntary sector (companions themselves).

Proactive companion care where early conversations can be started and shared, increase the awareness for statutory staff to ensure the needs of those who might be on the periphery of regular responses such as dying children and young adults are attended to (**everyone matters**).

05

All staff are prepared to care



How our service achieves ambition 5:

It is widely recognised that providing care to an individual approaching EoL can be challenging for healthcare staff to navigate. Access to specialist medical knowledge, resource limitations, emotional skill, and/or a plethora of other reasons are all barriers to effective palliative care. The Lancet (Sallnow et al., 2022) identifies the cultural and normative obstacles that are common to preventing an honest and sensitive conversation about EoL. Experience, expertise and case studies are shared throughout the training to empower companions to make **knowledge based judgements** with understanding non medical care needs. Enabling the conversation to be a process, or several discussions is a key element of the companion service. In this way **support and resilience** for all staff is enhanced

“General staff need time to look after people and their families at the End of Life. This is difficult to do well and training can help”, NIHR (2015).

The companion training provided to statutory workers develops and complements training received elsewhere re ReSPECT documents and EoL care. Given statutory workers are highly likely to have contact with patients at EoL, their ability to have these conversations confidently and sensitively is essential to providing patient-centred care and enhancing **professional ethos** within the care system.

For the companion volunteers strict **governance** safeguards are in place to ensure patient and companion safety. Throughout the training and subsequent supervision of companions attention is given to **legislation awareness** for both the statutory and volunteer teams

06

Each community is prepared to help

Volunteers

Practical support

Public awareness

Compassionate and resilient communities



How our service achieves ambition 6:

Guidance from NHS England (2023b) discusses the Outcome: Each community is prepared to care. This service gives **practical training and support** thereby directly contributing to this target through meaningful engagement (asking patients what they need and involving project participants in designing its structure and improvements), improving health literacy (hosting information and awareness-raising stalls at local events), community mobilisation (using volunteers and statutory workers already embedded in the community), and empowering patients to make decisions regarding their health care. This builds **compassionate and resilient communities**.

Carers are often a key but under-considered component of providing care to patients. The Compassionate Companion Service provides support and empowerment to carers through holistic care. Community preparedness is further embedded through the majority of contacts taking place outside of medical establishments, reducing healthcare professional dependency and recognising the importance of holistic support in relation to medical needs.

Utilising the community, its knowledge and lived experience through effective engagement can lead to better outcomes and increased social capital (WHO, 2023).

Each community is prepared to help

We have become separated from the innate knowledge, skills and inner wisdom we have to care for our own – those who may be at end of life, elderly, living with a terminal illness or dementia. Care has been largely handed over to experts and institutions – the NHS, hospitals, care homes and so on.

Day by day we see these institutions are underfunded and overstretched – unable to provide the compassionate care we would want for ourselves and those important to us. We also see the benefits of citizens and communities coming together to care for their own. We want to share the knowledge and skills we have acquired as Compassionate Companions working in their communities, so they are better equipped to support the people they love, their friends, their neighbours, people in their communities. This programme is designed to bring dying back to where it should be – in the heart of our Communities with everyday people having the confidence and competence to care for others. Your involvement and role is key and you are part of a necessary and much needed movement of how we care for our 'own' at end of life.

Professor Allan Kellehear – Medical sociologist and author of Compassionate Cities



Word cloud of volunteer descriptions of how it feels to be a Companion

With the reduced number of healthcare professionals per patient in coastal communities (Whitty, 2021), it is particularly important to improve community mobilisation and build local volunteer capacity to support End of Life care.

The Compassionate Companion service won The 2023 Suffolk Community Colonel Probert award 'recognition to a group that has worked for the benefit of the Community'



Case Study - Mr S

Mr S was 74 years old when diagnosed with early onset dementia. He presented with his son soon after diagnosis in fear of what the future holds. When asked what his worst fears were he was clear that he was terrified of losing control over his choices.

He consented and was matched with a companion who has supported his Advance planning wishes whilst he still has capacity including where and with whom he would be happy to be cared for and other care wishes.

His son has been supported with completing Power of Attorney whilst Mr S is still able to consent. With this support we can be as proactive as possible in honouring his choices and getting it right for him and his loved ones.



Case Study - Paddy

Paddy was a 79-year-old man, living alone in a very remote house outside a little village. He had recently had a diagnosis of lung cancer and had a background of severe respiratory disease. I visited him for a conversation around future planning. He was keen to meet a Compassionate Companion to help him understand the choices he had and to share his care wishes. Importantly, he wanted to update his will and had no resources to do this.

Over several visits and compassionate conversations around death and dying, his resuscitation status and care wishes were understood and recorded in the ARC forms. With the support of the Compassionate Companion Service, he also completed his will.

Paddy expressed a clear wish which he even expresses in the documentary film that he featured in:

"If I was found on the floor conked out, I would prefer to be left alone - let me go."

Paddy died with all his wishes honoured, at home and with his friends around him.



I mean I don't even know how to write a will



It would be nice to know so I can sort my affairs out.

After death, Paddy continues to bring warmth to those around him supporting the Compassionate Companion Service by having designed the daisy logo.



Costings

Outgoings 2023-2024

Table 2 - table of project costs for FY2023-2024

Item	Cost
2 days per week clinical coordinator – Band 7	£23,187
2 days per week operations administrator – Band 2	£9,753
Lead GP	£6,000
Sundries (Mandatory training, IT, and disbarring costs)	£5,000
Bespoke compassionate companion and clinical training	£5,000
Training	£5,000
Management costs	£8,091
Total	£62,031

Projected outgoings 2024-2025

Table 3 - table of projected costs for FY2024-2025

Item	Cost
Clinical coordinator – Band 7	£19,500
Assistant clinical coordinator/administrator – Band 6	£12,000
Assistant administrator - Band 2	£1,500
Lead GP	£12,000
Sundries (Mandatory training, IT and disbarring costs)	£6,000
Training programme	£3,500
Management costs	£8,000
Total	£62,500

This breakdown covers the same geographical area as 2023/2024 (Ipswich and East Suffolk). When the service expands further funding will need to be considered.

Future Opportunities and Challenges

With secure recurrent funding the companion service could be embedded into the ICS to support the fulfillment of the national must do's. Current funding provides for Ipswich and East Suffolk Alliance and additional investment is needed to grow the service to the full area of SNEE ICS.

Recruitment and retention of volunteers has been a challenge that resonates with any volunteer organisation and with regular engagement activities we are confident that the service can grow from strength to strength. Many of our existing companions come with great skills including social media knowledge, clinical backgrounds, community group advocates, having the confidence to join with clinical teams to promote awareness at every opportunity.

We are also mindful that there is a higher concentration of companions around Ipswich and East coast Suffolk. To expand the service there are plans (pending future funding) for a campaign to raise awareness amongst all GP practices and Patient Participation Groups (PPGs), aiming to recruit at least 2 volunteers per practice to be ambassadors for their communities in compassionate companion care.

We are working closely with the Frailty Assessment teams at Ipswich Hospital and collaboratively developing how to optimise Advance planning conversations for all appropriate patients using the companion service.

Plans are in place to redesign the Survey monkey questionnaire to be more simple and easy , collecting salient information for further evaluation (i.e. more skillful measurement of impact/outcomes).

Training statutory staff is showing its positive impact already on reducing inappropriate admissions – we see a direct correlation between patients referred by the frailty teams from non-trained care homes compared with none from those who have had compassionate companion training – suggesting proof of the hypothesis that with training avoidable hospital admissions can be achieved.

Furthermore, many of our Champions volunteer their time outside of their work role for the benefit of their own community, citing 'I'm so inspired by this service' and ' I wish this service had of been there for us when mum died' as reasons.

Companions enable every person in the service in their last year of life to be fully involved in the ARC of dying well.



Final Word

The companion service is a unique, courageous, and trail-blazing initiative. Nowhere else have we seen such true integration across all health and care organisations, where volunteers are involved in the delivery of individualised advance plans as part of a dying person's personalised care and health support plan. Nowhere else have we seen volunteers having a caring, responsive, well led, and safe role as part of the multidisciplinary team in such complex care.

Furthermore, the Companion service is cost effective by improving GP access and capacity, reducing unwanted and avoidable hospital admissions, and supporting the wellbeing of the dying patient and their loved ones.

With demands on the NHS outweighing capacity and the growing complexity of care in our increasing ageing population there is a burning platform of things to be done differently. We have an opportunity to harness the compassion and competence in our communities.

This report highlights the multitude of gains attained and the art of the possible if recurrent funding is secured for future service provision to be embedded as compassionate business as usual.



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The Peninsula Practice

A Collaboration of Compassion





**This Report has been written by Boogie Thompson and Guy Peryer * PhD, CPsychol, CSci, FRSA.
Graphic design by Julia Barry**

The Compassionate Companion Service is currently funded by the Suffolk and North East Essex Integrated Care Board to provide the Compassionate Companion service across the area of Ipswich & East Suffolk.

The service is owned and delivered by its invaluable team of volunteers and champions in the face-to-face, heart-to-heart, day-in-day-out, support for our dying patients living in our communities, and is for our communities. It is facilitated by the clinical team of Dr Lindsey Crockett (GP), Kathryn Barber (nurse specialist) and Bill Thompson (health care therapist). Special thanks to Sheila Stoker (recently retired) for her skills and operational initiatives, and devotion to the service.

The team is supported by the invaluable collaboration of IES alliance colleagues, our primary care practices, integrated neighbourhood teams, acute hospital trust clinicians, hospice teams and affiliated organisations including End of Life Doula UK.

Thank you on behalf of everyone who is going to die, for reading and learning about our work to support a local approach to the ARC of Dying Well, with the aspiration that this may be a framework for a national approach for the delivery of excellent End of Life Care across the UK.

For any enquires please contact our clinical team at bill.thompson1@nhs.net

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The Peninsula Practice

A Collaboration of Compassion



Advance Care Planning:

Methods of avoidance
for Doctors*

*inspired by original
research



1. DENIAL



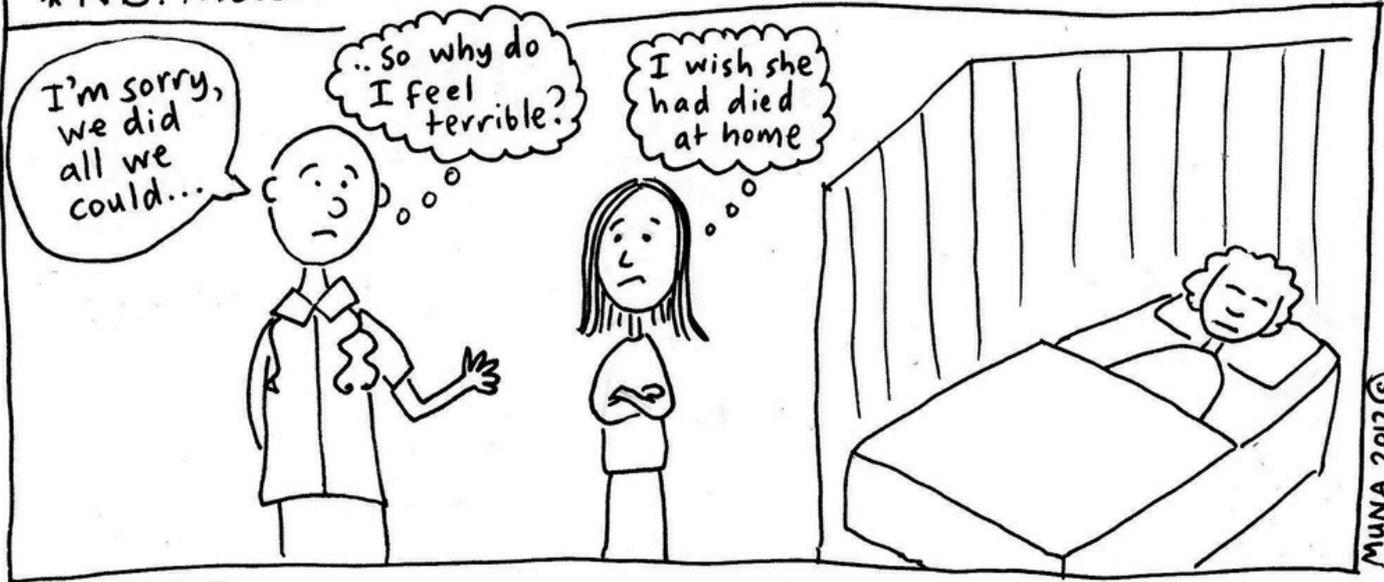
2. DEFER RESPONSIBILITY



3. PROJECTION



NB. AVOIDANCE CAN HAVE ADVERSE SIDE EFFECTS



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