Compassionate Communities

Final Report & Evaluation of the **Compassionate Communities** Pilot Project

March 2021

NHS

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COUNCIL

The Peninsula Practice

Introduction

In this report,"Compassionate Communities" is a project developed and delivered at a community level, through the Peninsula GP practice, in East Suffolk.

Compassionate Communities is a well-recognised Public Health approach to end of life care.

The project emerged because of a local desire between medical teams and the community to work together and support each other better in end of life care.

> *"Recent studies conducted in the world's most industrialised nations reveal that access to palliative care is both inadequate and unequal. The problem is exacerbated by the exponentially growing need for this type of care due to the world's rapidly ageing population. These findings have prompted governments to address the problem, most often with new legislation and the allocation of more resources. Despite these efforts and a definite improvement in access to palliative care, important inadequacies and inequalities in access to these services persist. A paradigm shift in the way palliative care is seen and implemented, inspired by new research and pioneered by the work of Allan Kellehear, could better serve the world's ageing and vulnerable populations: rather than continue to separate the sick and the dying from their communities in order to treat them in costly, depersonalising institutions, these patients would become a central component around which community services and professional care services would be organically interwoven. This new model, called the "Compassionate Community" model, is inspired by public health approaches of health promotion. Initial experimentation with such communities has yielded promising results, suggesting that the Compassionate Communities model could prove to be a viable alternative to the current approach to palliative care and to the overstrained system borne from it."* - Gabrielle Roy et al. Medical Research Archives vol 8 issue 5. May 2020

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Project Background

Compassionate Communities is a public health approach to end of life care. It is not a new idea. It is based upon the pioneering work of Professor Allan Kellehear and Dr Julian Abel, the founding umbrella body being Compassionate Communities UK.

In 2018 the Public Health Report in Suffolk: Lasting Legacies was published to tackle the social stigma around discussing death and dying. The report made the following six recommendations, which are:

- Addressing the social stigma around talking about end of life and death and supporting the people of Suffolk to be comfortable when discussing these matters
- Supporting advance care planning, with the associated documentation being consistently completed in conversation between professional and patient
- Embracing compassionate communities that involve people in their own end of life care, and a holistic approach that goes beyond the traditional health and social care services
- Encouraging greater understanding and health literacy among the population to enable people to have the skills, knowledge and ability to plan well for end of life
- Supporting professionals who care for the dying and bereaved to have a thorough understanding of the practices and rituals prescribed by different groups, faiths and beliefs for the end of life and to seek advice when necessary
- Promoting the importance of letting family know of each individual's decision around organ and tissue donation

At the same time, Dr Lindsey Crockett, senior partner at the Peninsula Practice in East Suffolk, was recognising a need in her small rural practice to improve knowledge and support networks for patients facing end of life, and their families and carers.

Working with the Public Health Locality Lead for East Suffolk, Rachael Metson, a community development approach was taken to explore ways of building a local compassionate community response. Together a number of local conversations were held with community members and a community meeting was held in Hollesley Village Hall in November 2018. It included other key charities working in this field, St Nicholas and St Elizabeth Hospices and CRUSE; the local Good Neighbour Scheme; and other community groups such as the Women's Institute. Patients of the medical practice who had experience of supporting loved ones at end of life also attended. These discussions provided evidence that there was a real desire to improve things locally and importantly a passion to be part of it.

Notes made from conversations with Community by Dr Crockett, 2018:

"It emerged from these reflective exercises that every person present at that meeting had experiences of end of life care for others from which we, as providers, needed to learn from. The overriding theme was lack of time, recognition, and preparedness for dying patients and their families; with the medical profession unable to provide adequate care, let alone fully holistic and compassionate care.

It was apparent that with the annual national mortality rate of 1%, it is not possible for any single organisation to provide all our patients all the care they need when they are identified as having an incurable illness. An average GP practice will have one patient die on average every week.

The vast majority of people die calmly without the need for medical intervention. A person who is considered to be in their last 6 months of life has relatively less needs for medical intervention. Most of their living is filled with opportunities, similar to a birth plan, when they can prepare and consider choices such as place of death, make or update a will, reconcile relationships, prayers and music for funeral etc.

These plans and choices have little to do with clinical needs yet unless the clinical teams know the plans, there is a risk that in a crisis situation they will be dis-honoured for example, patients being resuscitated against their wishes, or admitted to hospital to die, perhaps ventilated against their unknown wishes, or put on long term life support when, had there been a conversation and wishes made know, this would not have happened." - notes from Community conversations by Dr Crockett, 2018.

Dr Crockett is also part of the Clinical Executive Group at Ipswich and East Suffolk Clinical Commissioning Group (CCG) and Lead for End of Life Care. She took this evidence to the End Of Life Programme Board and with it a project proposal which had been developed with the Public Health Localities Lead, and informed and shaped by the community. The Board was keen to understand and test out a proof of concept and so this work formed a new theme in its strategy in 2019: "Compassionate Communities". This theme adopted exactly the three work-streams of the Peninsula Practice Pilot project:

1 - Communities have skills, capacity and networks to support each other before and after End of Life (EOL)

2 - Improve Death Literacy

3 - Reduce the stigma attached to EOL

Project Funding

In 2018/2019, Dr Crockett and Rachael Metson researched and developed a full proposal to develop a local Compassionate Community. The Peninsula Practice was successful in securing funding for this two year test project from:

- East Suffolk Council, specifically to train local community volunteers as "End of Life Doulas", or what were later called "Compassionate Companions".

- Ipswich and East Suffolk CCG to put in place the infrastructure to support the project, including a 0.4FTE Project manager and monthly group supervision by an accredited psychotherapist. It also enabled 2 companions and Project Manager to undertake full diploma level training and share this learning. In addition, the CCG embraced the concept of using Creative Arts to reduce the stigma attached to End of Life and to improve death literacy, and allocated funding to this activity too.

Total Fund: 90000: of which 80000 CCG; 10000 Hidden Needs Grant from East Suffolk Council

- Project manager Salary: £34500 (@15 hrs per week)
- Psychotherapist monthly Group Supervision: £8400
- Foundation doula training with Living well dying well: £10000
- Diploma level training: £8780
- Communications (leaflets/flyers/designer/print costs/survey monkey/website/mobile/death conference): £4000
- Film: £7875
- Schools project ringfenced (£3700 (willow project) + £5400 (schools) = £9100 to be held by St Elizabeth Hospice;
- Unspent due to covid-causing delay - ringfenced for reducing death literacy with Doula UK: £7641

Project Scope

Compassionate Communities are networks of people supporting each other to live fully before we die. By empowering communities we can support each other to be prepared and enable a good end of life wherever possible.

The project sought to:

- Train and equip local volunteers as Compassionate Companions to support people through end of life, working alongside healthcare professionals

- Enable people to discuss and make informed decisions about their own end of life, whenever that might happen and however far away that might be

- Encourage people to talk openly about death so that they can feel empowered and be confident in their choices

- Remove the stigma attached to end of life and see dying as part of living

- Enable local health professional to join in that training alongside volunteers so that they could incorporate that learning into their daily work

On this basis the Project identified three work-streams:

1 - Communities have skills, capacity and networks to support each other before and after End of Life (EOL)
2 - Improve Death Literacy
3 - Reduce the stigma attached to EOL

Evaluation

Colleagues in Public Health helped to create an evaluation framework adopting a logic model and this report will follow that framework. A logic model is a hypothesised description of the chain of causes and effects leading to an outcome. Data capture methods were put in place across all work-streams and, in particular, as soon as the Compassionate Companions were matched to patients.

The Tools Used
At the start of the project, a tool for reflection was developed for the Compassionate Companions to capture information. This was in the form of a survey monkey questionnaire that could be completed electronically or as paper copies if preferred for the Project Manager to upload.
The purpose of the questionnaire was to feed the evaluation, although some of the questions provided a means for the Project Manager to have an overview of activity, flag areas of concern, and seek timely ways to respond accordingly.
It included an emphasis on reflection:

- What went well?
- What did not go well?
- What could be improved?

It also asked how the volunteer was approaching Self Care.
The questionnaire split itself into 3 phases:

- Phase 1 - Initial and ongoing interaction as a Com Com
- Phase 2 - During the Dying Phase
- Phase 3 - After death

The Data
The patients ages ranged from 59-83 years old, six were female, two were male.

The full questionnaire, which was completed after each face to face interaction with a patient, generated 60 responses.

A telephone contact questionnaire was put in place when COVID restrictions prevented face to face contact. It generated 79 responses from March to mid December 2020.

Presentation of Findings
The onset of the Coronavirus Pandemic in March 2020 had a significant impact on project delivery.

This report presents activity delivered and planned against work streams, in terms of the project inputs, interventions and outputs that the Logic model identified.

The final chapter looks at lessons learned and recommendations.

The report has been put together using, where possible, photographs of the project activity. It includes contributions from the volunteers of the local area too, part of their appreciation of the community we live and work in, and enjoy as part of self-care.

Work Stream 1

Communities have skills, capacity and networks to support each other before and after EOL

2a) Governance: strategic leadership, management and governance arrangements to ensure delivery

The Ipswich and East CCG End of Life Programme Board identified “Compassionate Communities” as a new work stream for 2019, on the back of this developing pilot work. The Board received regular reports on the Compassionate Communities project. The End of Life Programme Board’s (EOL) membership includes:

- **East Suffolk & North Essex Foundation Trust,**
- **East of England Ambulance Trust,**
- **Local Hospices in Suffolk and Essex,**
- **Suffolk County Council Public Health and Adult Social Services,**
- **GPs and consultants.**

A “Compassionate Communities” Project Steering Group was established with Terms of Reference. Member organisations included:

- **Suffolk County Council: Public Health**
- **CCG: Transformation lead until Nov 19, with Dr Crockett on Clinical Executive Group**
- **Integrated Neighbourhood Team Manager**
- **East Suffolk Council Communities Team**
- **Speech and Language Therapy Team Lead**
- **Voluntary and Community Sector: St Elizabeth Hospice**
- **Local Business: Funeral Director**
- **Community and Voluntary Organisations: Community Action Suffolk**
- **Patient Representatives from Patient Participation Group and Ipswich Hospital**

A Creative Arts subgroup was established to adopt creative approaches to improve death literacy and reduce stigma at end of life. It had its own Terms of Reference and was responsible for developing activity within its associated project budget in relation to two of the Compassionate Communities project aims by adopting creative approaches to improve death literacy and reducing stigma at end of life. It aimed to do this by:

- Capturing best practice globally
- What was happening locally or had happened in the past and sought to build upon this
- Developing activity with other voluntary sector organisations or community groups either by:
  - direct commissioning/grant funding or
  - by direct delivery, utilising existing skills and resources within the Compassionate Communities project

2b) A community volunteer offer of Compassionate Companions is in place with EOL patients identified and appropriately supported by a Compassionate Companion

Early research looked at a number of EOL volunteer models for set up, training and management. These will be reviewed in Chapter 5.
The key elements required to put this offer in place are discussed below, including analysis of how this offer worked in practice.

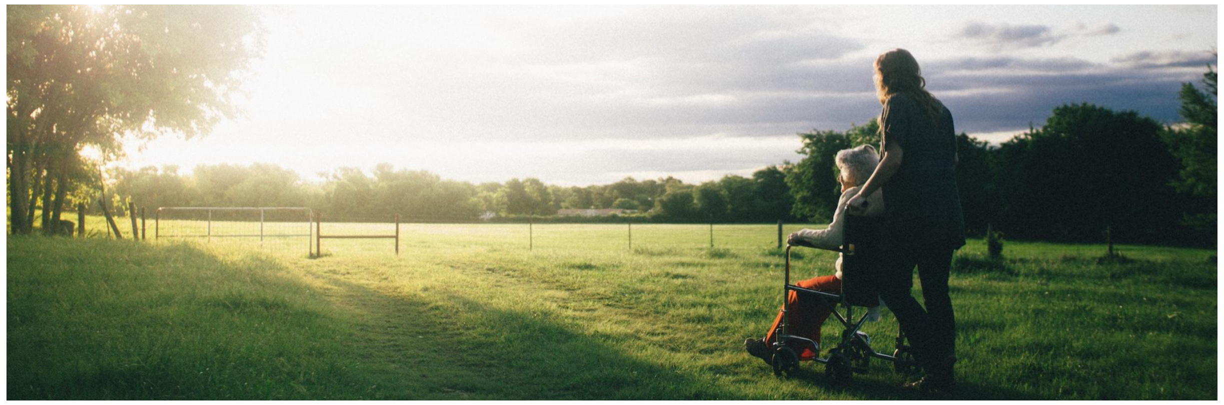
• Policies and operational framework

Drawing upon the support and experience of Community Action Suffolk and End of Life Doula UK, the Project Manager drew up the following policies and operational framework:
Code of Practice: Values and Principles
Equality and Diversity Policy
GDPR Training and Guidance
Health and Safety Guidance
Lone Working Guidance
Privacy Policy
Volunteer Expenses Policy
Safeguarding Policy and Procedures
Volunteer Compliance Statement
Volunteer Diary and Introduction Notes
In addition, the Medical Practice took out group insurance for the volunteers

• Defining the role of the Volunteer Compassionate Companion

A clear communication of the Compassionate Companion offer was set out in an introductory leaflet.

The role naturally mirrored the role of a doula with End of Life UK, as one would expect given the training and principles embraced. However, in recognition that most of the volunteers completed only the foundation level training with Living Well Dying Well, the project adopted a different name from doula: a Compassionate Companion. The language used to express the Compassionate Companion offer was carefully considered, simplified, and reviewed by Patient Representatives of the Steering Group.



A Compassionate Companion can:

- **listen to you**
    - spend time with you
    - help you feel safe and at peace
- **support you and your loved ones to think about your wishes including**
    - how you want to live until you die
    - what you need at the end of your life
    - where you want to be cared for
    - making plans, advance statements and important decisions
- **tell you about local support groups**
    - help you live your life as fully as you can;
    - help you get to know the people in these groups
- **offer practical support including**
    - help with small tasks; walk your dog
    - come with you to appointments or social events
    - read aloud to you
- **offer support to you and those around you during the dying phase**
    - they will see the signs that death is near
    - be ready to bring comfort physically, emotionally and spiritually.
    - work alongside professionals
- **offer comfort, information and support to the family after death**
    - help them know what to do next and when

• Identification and recruitment of volunteers

The GP Practice led the identification of volunteers and a decision was taken to not widely advertise for volunteers. It was important to the lead GP that there was some existing connection to volunteers either through the practice as patients or through living and working in the local community.

"I was approached by Dr Crockett and other staff at the Practice. As I am now retired it seemed a very good way of helping in the local area. The finer details were discussed later but I needed something to keep me mentally stimulated and involved in the village. As you know, I love talking to people, so this was a wonderful thing to stimulate me. Also there but the grace of God we might need that help ourselves."

"The Chair of the Good Neighbour Scheme, who had been involved in an initial community meeting, sent me an email with the information about this project potentially and wondered if I would be interested, given that she knew me and my work experiences (after many years ago having given home care to people at EOL in Africa). I then contacted Dr Crockett who gave a sketch outline of how she hoped to fulfil the project aims & objectives and invited me to join the other people who had put themselves forward as volunteers for further explanation".

"In the spring of 2019 I joined a friendly group who were invited by Dr Lindsey Crockett to learn about how we could support anyone moving towards and reaching the end of their life on the Deben Peninsula. We came with different skills or experience. I came along as a long since retired SRN and RMN, but also someone who is interested in helping people and supporting the local community. I have had experience of bereavement and looking after my husband at home during his last months with cancer. I have also spent time with sick and dying people within my family, church connections and a healing fellowship."

There were a number of community and group meetings of interested volunteers to support these introductions and the induction process.

"With the various initial group meetings that were held in 2018/2019 at the Community Centre the extent of the role and commitment gradually unfolded, was explained and understood with discussion and questioning and then elaborated on further in LivingWellDyingWell foundation course."

All training participants submitted a written precis of their interest in this work, life experience, and values to LWDW in order for the training provider to accept them on the course. Volunteers all had to undergo an enhanced DBS check.

Volunteers were asked about the potential time commitment, availability, and distance they might be prepared to travel, albeit matches of volunteer to patient always aimed to be as local as possible to foster the community response. In hindsight and possibly this was impacted by COVID and lockdown, these questions were less relevant in practice.

Eight volunteers agreed to commit time to the training in order to volunteer, one of whom decided to withdraw part way through. The training was also offered to an additional seven professionals working locally: Alongside the volunteers, members of the Integrated Neighbourhood Team participated: a district nurse, the Integrated Welfare Practitioner and a speech and language therapist; together with a Motor Neurone Coordinator at St Elizabeth Hospice, a carer from a local Care Home, a nurse working with marginalised and vulnerable adults, and the Transformation Lead at Ipswich and East Suffolk CCG, who later became the Project Manager.

• Training

Choosing the Training Provider

After research, it was decided to work with Living Well Dying Well (LWDW) for the delivery, but also because of the ongoing support and learning that would come with it, provided by End of Life Doula UK. Once learners have completed their Foundation training, they are eligible to join End of Life Doula UK, (EoLDUK), part of the Living Well Dying Well Network. The Association brings members together with each other in regional networks, on-line, at events and professional development days. This sharing of experience gives everyone the opportunity to grow individually and as a community of practice. End of Life Doula UK gives practical on-going support and mentoring.

The Foundation Course

Introduction to a Person-Centred Approach to Death and Dying is a stand-alone Crossfields Institute Continuing Professional Development (CPD) programme. It forms Part 1 of the **LWDW 'Person-Centred Approach to Death and Dying' Diploma,** but can be taken as a stand-alone course. The full Diploma has the **Crossfields Institute Quality Programme Mark.**

The funding provided the opportunity for some volunteers to progress to Diploma Level.
Crossfields work primarily with education providers who are interested in facilitating deep learning and a journey of transformation for their learners. Crossfields Institute is an awarding organisation that is regulated by Ofqual (the Office of Qualifications and Examinations Regulation).

The Institute is a charity working to promote holistic, integrative education and develops specialist qualifications for vision-based organisations, centres and colleges in the UK and overseas. Their holistic approach to education aims to encourage cognitive, practical, emotional and spiritual development, supporting learners to reach their full potential and become active citizens.

LWDW'S delivery approach is holistic; taught skills are accompanied by experiential work and reflection to nurture and facilitate personal insights. Each individual contributes to the learning experience and knowledge base of the whole group.

The Foundation course **'Introduction to a Person-Centred Approach to Death and Dying'** was delivered as a 5-day face to face course, over two and three days separated by 6 weeks. For the first time LWDW delivered the course to a cohort of 15 people all living and working in the same small locality. The first sessions took place in April 2019 at Butley Priory and the remainder in June at Snape Maltings.

Because of the immersive style of learning and the subject, LWDW know that in all their courses, with participants from across the UK and internationally coming together, strong and lasting relationships are developed between participants. Those from this project who went on to the Diploma will reinforce this; the network of compassionate people that forms is strong. Therefore, to deliver a course attended only by people living and working in one community did not simply increase knowledge and skills about End of Life, it created a bond between attendees that was surprising and very beneficial to the delivery of the project.

The Foundation Course Content

The Foundation course consisted of 32 guided learning hours taught in 5 sessions. Individuals had a choice whether to complete the two assignments to embed that learning which involved an anticipated further 25 hours of independent learning. This was a requirement though for any individual moving on to Diploma level. There was also a recommended reading list.

Content focussed upon four themes:

Theme 1- Understanding the dying phase

- Including: the emotional, psychological, spiritual and physical responses that can be expected from someone who is dying and the physical changes in a person who is moving closer to death.

Theme 2- Understanding the effects of death on those who are caring

- Including: models of grief and the consequences of it pre and post death; and the possible factors affecting a carer's ability to care.

Theme 3- Engaging with the Doula role

- Including: practical information about caring for a body at death; but also an exploration of own values and beliefs, the significance of and how to build trusting relationships and the importance of and self-care, self-reflection and personal development, and how to achieve these.

Theme 4- Choices and requirements at the time of death and dying

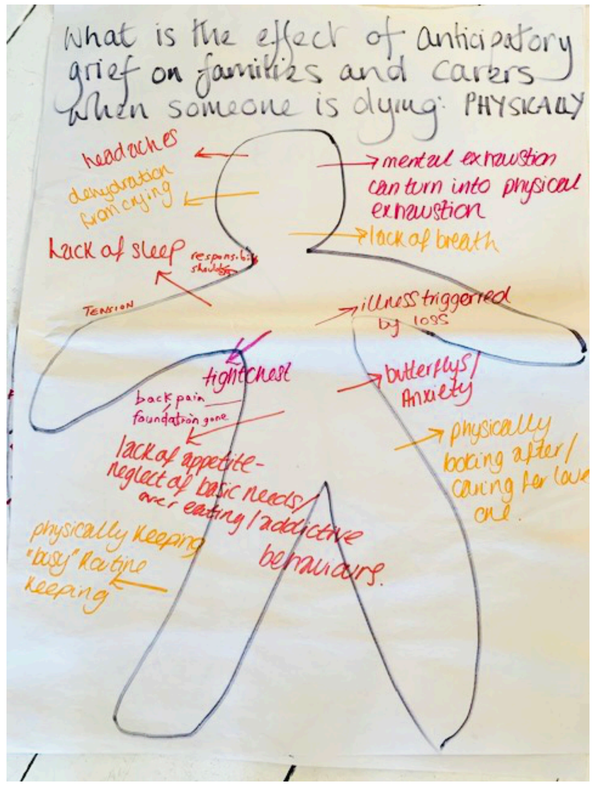
- Including: Advance Planning, funeral options, customary practices and legal requirements, religious and cultural practices.

Style of Learning

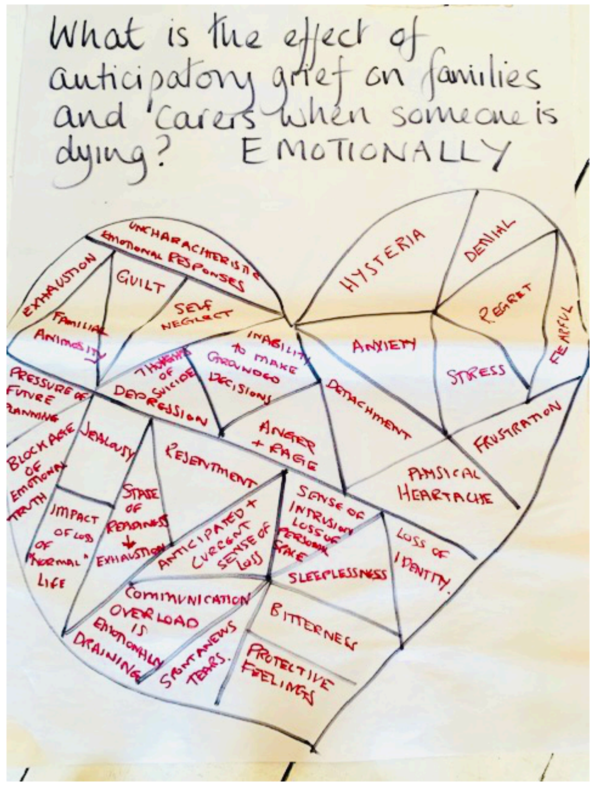
The learning often commenced with a guided meditation and reflective practice, before whole group discussions, smaller group exercises or in-depth exploration of personal experiences and reflection in pairs.

The inclusion of health and social care professionals in the training programme, all with End of Life experience and clients, brought a richness of discussion and even the trainers commented upon this.

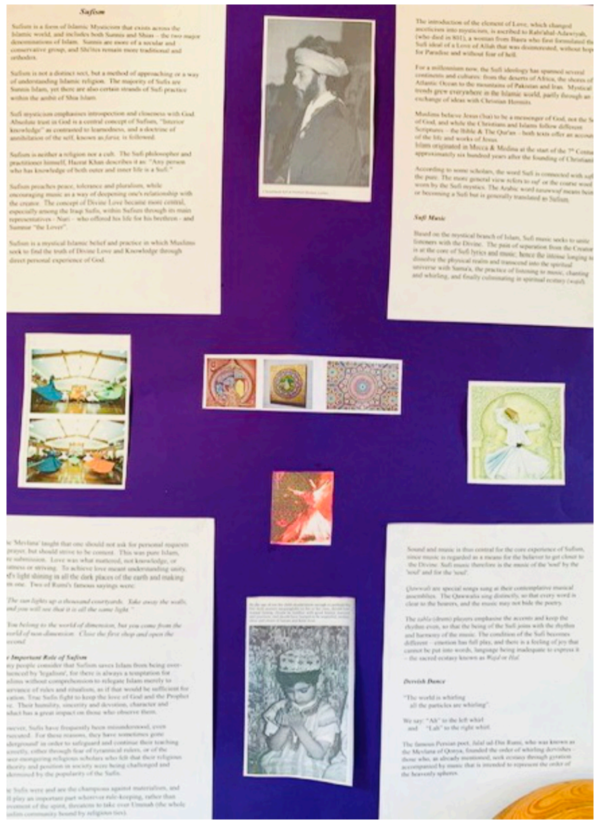
Most importantly, given the various backgrounds and learning style of participants, the style of working was inclusive.

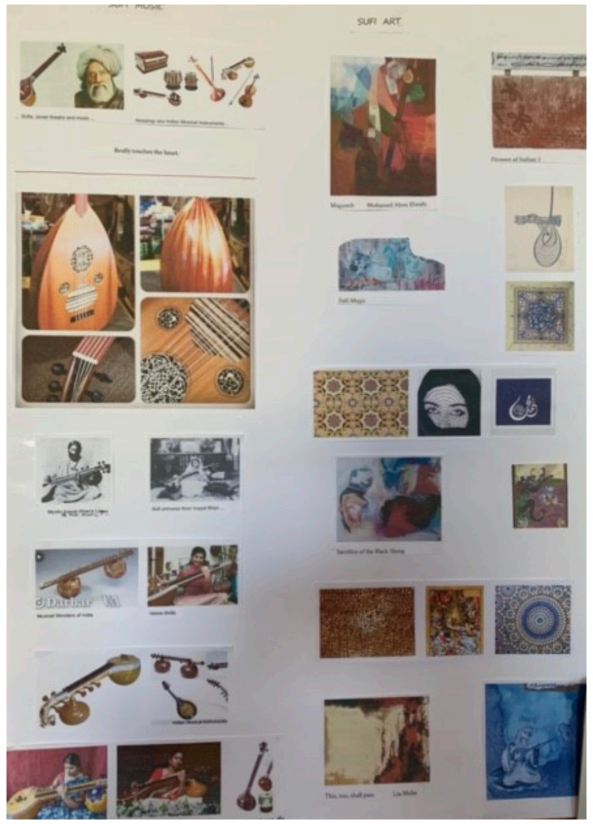


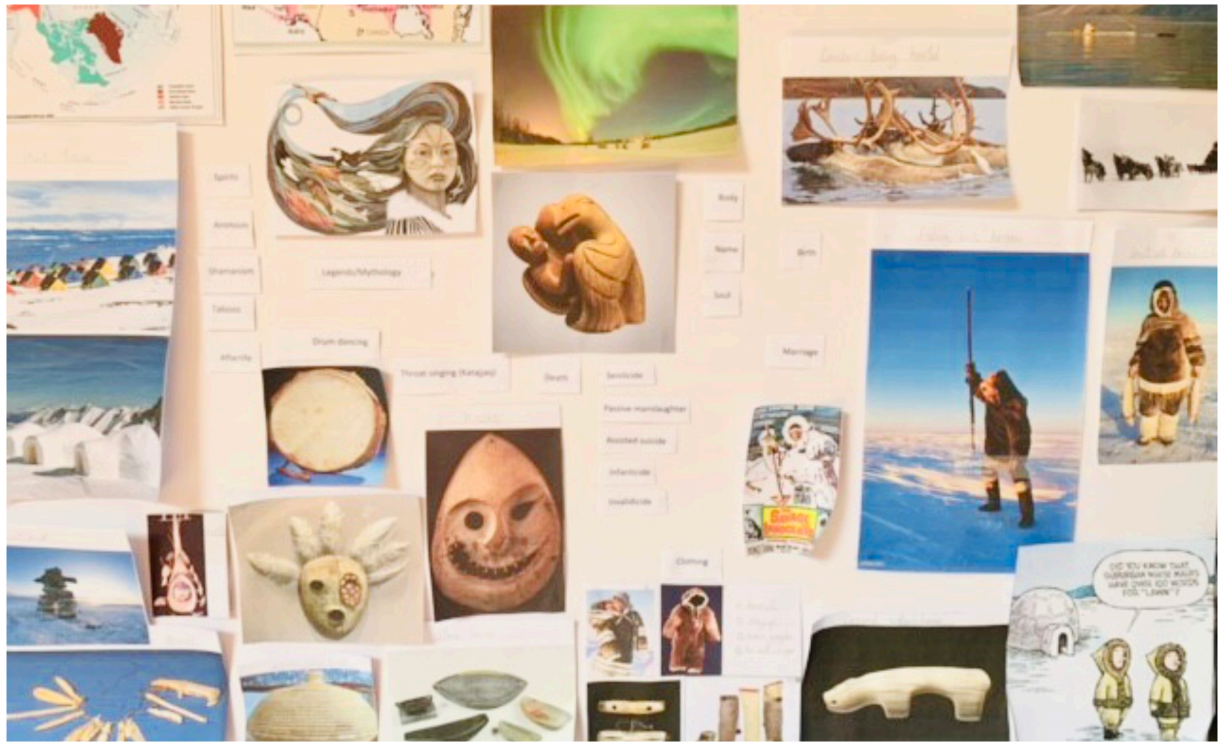
Subjects would be broken down into bite-size chunks for smaller group exploration, then fed back and shared with the whole group. For example, here, three groups explored the impact of anticipatory grief: physically, emotionally, and in a social context.



A piece of research into End of Life beliefs and practices across different cultures was undertaken as homework, and each had to present this back to the group and share learning. Participants had freedom and creativity to do this.







One participant chose to do this very interactively as can be seen here:

Foundation Course feedback

Nine people who attended the course completed the evaluation soon after it was completed.
They were asked to score on a scale of 1-10 what they considered their level of knowledge about End of Life was before and after the 5 day course. There was a clear improvement in knowledge across all participants.
They were also asked about their level of confidence in supporting someone at End of Life and again there was a very positive feeling of increased confidence after the course.
All volunteers said, that from their perspective, the quality and depth of EOL Doula Training provided by LWDW was sufficient for them to move forward in this project.

Other comments included:
"The trainers were excellent"

"It was fantastically informative"

"The training and books I read: Being Mortal and With the End in Mind were all excellent"

"It was explained carefully and with compassion"

"As an inexperienced person in these situations I am still unsure what is expected of me"

"I embraced the learning as best I could, my only concern being that I am over 80 and don't remember things as well as I used. In a face to face situation, unable to take notes, I might have difficulty recalling all I heard."

Towards the pilot end in January 2021, Compassionate Companions were again asked to reflect on the training, now that they had used that training in the Compassionate Companion role:

"The five day training course covered many basic rudimentary subjects pertaining to being in the presence of a person nearing the end of their life. It left one with thought-provoking challenges - covering mental, emotional, physiological & spiritual aspects of a person's life - which could only be put into practise by going into the homes of individuals, experiencing that particular person and their individual needs and then applying what had been covered on the course according to those needs. Ultimately though, it was only ever going to be an introductory session without the depth and expansion clearly needed by a Compassionate Companion /Doula when facing the stark reality of meeting someone struggling with the transition from this world into the unknown with all that that entails."

"On the initial afternoon the information was clear, and yet, as I recall over-powered by the professionals. I think I was looking for a project, and so was carried along. But was a lot I gained. I have no regrets and completing the course, meeting another group of people, a profession I have not had the chance to be Involved with. I felt comfortable, valued and appreciated."

"I think there could possibly have been more emphasis put on the multiple sharing by all teams involved with the patient and quite where the Compassionate Companion may fit within that whole".

"On a personal level and after many years ago having given home care to people at EOL in Africa, it was a positive experience to be brought right up to date, with the overall community care resources being offered to those living in rural areas in Britain who may be remote, cut-off from social interaction and living alone, in some cases with family living far away. The practical considerations for this 'wrap-around' care to hopefully be delivered to an individual at EOL are wide and it was good to hear the shared experiences of the leaders of our training course whose testimonies bore out the reality of what we as trainee volunteers could expect and commit to."

"Other training later given on Health & Safety/Policy etc were very welcome and needed."

"Those unable to carry on to diploma level as a doula I believe need refresher courses from time to time."

The Optional Assignments

Three people completed the assignments. Most were content with the depth of training already provided for their volunteer role, and felt no desire to embed this learning.

This did form the progression work for the diploma and involved:

- Case study scenario: (2500-5000 words) which needed to evidence and cross reference the foundation course learning outcomes
- Reflective comments (500-1000 words)
- Plus three appendices from work completed on the foundation course

The case study was most challenging because of the need to cross reference and evidence learning outcomes. The three learners shared some of their work and supported each other in order to successfully complete and move forward in a timely way to Stage 2 – the Diploma.

The Diploma

Two of the seven volunteers who completed the foundation training took the opportunity to go on to complete the Diploma. They did this together with the Project Manager. The course is portfolio-based learning and is externally monitored and certified by Crossfields Institute. The full 20-day programme has been awarded the Crossfields Institute Quality Mark.

The programme consists of 104 guided learning hours, made up of taught sessions, and 182 independent learning hours comprising reading, and personal reflection, as well as completely assessment tasks.

In addition, learners are required to demonstrate a minimum of 20 hours of practice within two or more of the following contexts:

- Hosting conversations about death and dying within your social network
- Creating and participating in community events to raise the profile of death and dying
- Supporting people to complete Advance Care plans
- Volunteering with organisations such as Marie Curie, Macmillan and Hospice befriending or home sitter services
- Volunteering in nursing homes or hospitals

Two case studies are required, which enable learners to tell the story of the clients that they work with and demonstrate the application of their learning and understanding. Each case study had to be between 1500 and 3000 words.

Learners are required to submit a portfolio of evidence for this programme.

There are six themes:
5. Complementary and Creative Approaches at End of Life
6. Working with Spirituality at End of Life
7. End of Life Person Centred Practice
8. Understanding Relationship Dynamics at End of Life
9. Personal and Professional Development for End of Life Doula Practice
10. Case Study Unit

The Diploma Course Stage 2 is a six-day course and the second part of the full 20-day End of Life Doula Diploma training. It was held over two blocks of three days in Lewes, England.

Themes covered include:

- Self-care building resilience
- What I bring to the Doula role
- Volunteering opportunities
- Exploring boundaries
- Practice issues – signposting & safeguarding
- Mapping the family tree
- Family relationships and family dynamics
- Listening and communications skills
- Relaxation techniques -stress responses acute/chronic stress
- Appropriate use of touch
- Personal perspectives on life and death
- Dynamics of power and control in the helping relationship
- Practice standards /record keeping/LWDW Values, code of practice
- Involving your community
- Role of the Doula in hosting a community event

The Diploma Course Part 3 is a nine-day course, the third and final part of the full 20-day End of Life Doula Diploma Training. It is only available to learners who have completed the Stage 1 Foundation and Part 2 of the training. It was held over three blocks of three days in Lewes.

Themes covered include:

- Use of imagery and the use of metaphor
- Unconscious processes, acknowledging the shadow
- Maintaining healthy energy system
- Motivation for becoming a Doula
- Ethics, assisted suicide/ euthanasia/exit
- Reflective practice in the Doula Role
- Compassionate presence
- Palliative care symptom control

- Pain and suffering
- Spirituality, faith, belief and religion
- Role of the Doula in spiritual care
- Unusual phenomenon at the time of dying
- Complementary therapies in end of life care
- Reminiscence work
- The arts in end of life support
- The concept of the soul's journey
- Inner and outer practices to support the soul's journey
- Assessing needs of client and family
- Endings and new beginnings
- Withdrawing from a relationship

Style of Learning

Again, the course usually began with meditation and reflective practice. Modules were mixed-up across the days to provide variation, but this did tend to overly complicate the organisation and approach to follow-up coursework. The learning rests upon individual willingness to explore self: experiences, beliefs and fears. It is very intense and requires significant commitment. This included for example visualising one’s own death, writing a letter to loved ones, exploring own family relationships and values.

Exercises included creative work drawings and exercises such as using buttons and stones to reflect upon family relationships and support networks.

It also included watching films, listening to music and many small group discussions and work in pairs.

The diversity of participants' backgrounds from in the UK and internationally added real depth, because the course is designed to explore, contribute and learn from each other.

The course was delivered face to face but in light of COVID is now available as online only, or blended.

Review of Diploma Training

The Project Manager and two volunteers completed Stage 2 in November 2019 and February 2020. They moved quickly onto Stage 3 in March 2020, completing the 9 days by close of September 2020. There were specific challenges in rescheduling and delivery given the onset of COVID and lockdown. They all managed to do the in person training in Lewes but this was not without a commitment from all to complete in line with project timetable.

The three participants all had very different professional and personal backgrounds, skills and experiences to bring to the training and share, together with their learning and involvement to date in the Compassionate Communities pilot project timetable.

The training is intense and more so when undertaken over such a short space of time. Each struggled with particular but different elements of the training but together supported, and continue to support, each other in processing information and completing the portfolio. Similarly, they worked together embracing reflective practice.

"I often felt out of my comfort zone. There were some elements and approaches that were challenging for me, and contrary to my preferred style of learning. This seemed to be the same for everyone on the course at some point. The beauty of the immersive learning was that it develops a group with strong, internal, subtle support mechanisms to help each other through"

There was significant value on taking this journey together. Equally, they were able to use this time together to connect with other participants in the UK and abroad in order to nurture wider involvement in the Compassionate Communities Pilot, in particular the work using creative arts. This network should not be under-estimated and, together with their ongoing involvement in LWDW / End of Life Doula UK conference and regional meetings, presents very positive contributions to the pilot work but also the movement more generally.

After completion of the training, participants have five months to submit the portfolio. The three participants are committed to doing this, though the case study may be delayed as permitted, given the challenges currently in providing face-to-face support. All three continue to be active members of EOL Doula UK, participating in regional meetings, telephone helplines and working groups.

"This was one of the most challenging courses I have undertaken but the network of individuals that I met during Stage 2 and 3 have been inspirational in knowing that our work in Suffolk can really make a difference as part of a wider movement"

"Continuing the training over another 18 months for the full diploma meant being able to connect with a larger network of doulas and thereby gain wider knowledge from everyone's varied experiences and invaluable connections to go forward with. The training took us deeper, both compassionately and practically.

It was at times emotionally tiring, but the balance of meditative and creative practices gave me time to reenergise, reflect and respond instinctively and with laughter too. I am now actively supporting someone and I find the knowledge I have from the course incredibly helpful in deep listening with respect and compassion as well as practically having tools for opening up difficult conversations around End of Life, I would never have had the confidence to have these conversations before. I am deeply grateful to the opportunity I was given and the incredible people I am making this journey with."

"Our Foundation course ignited a spark which inspired me to dive deeper The diploma has at times been personally challenging; it has opened up and is continuing to open up new possibilities and ways of looking at things. It has been both expansive and evolutionary. It has opened up more doors and curiosity. I am learning to be more at ease with the sometimes uncomfortableness around end of life.
As a volunteer Compassionate Companion, I have for almost a year been accompanying and witnessing the journey of a woman with a terminal illness.
In my work in a care home I I have sat with people at end of life, read meditations from the course, simply been present and there to assist in navigating families raw in their emotions, via an iPad. I am practising and learning what the course embodied, it is a true privilege and honour. I am extremely grateful for this incredible journey and to the people who pioneered the Compassionate Communities Project who made it all a possibility. With heartfelt thanks and appreciation."

Feedback from Compassionate Companions on how the LWDW training equipped them with the skills to volunteer.

In the regular feedback questionnaire, the Compassionate Companions were asked if they felt that their training, received through the project to volunteer as a Compassionate Companion, had given them the appropriate skills and expertise to introduce options to the individual/family/carers or ideas not previously known about.
One Compassionate Companion responded:

- *"I've learnt simply to hold space with this lady"*

Other responses relate to areas within the LWDW training that focus upon complementary therapies and use of the creative arts:

- *"Meditation practices ."*
- *"Creative and Therapeutic practices."*
- *"Suggestion of making a memory box or writings, with photos and travel memories recorded."*

- *"In a previous chat on the phone I signposted about tres and recommended facilitator as my companion was talking about shock thought it might well be beneficial, gave her the info."*
- *"We discussed the creative use of music - individual likes listening to radio music as a way of not feeling so isolated...we talked about favourite tunes/songs/singers and various other venues outside the home where music could be listened to with others for company (although at time of writing given the Coronavirus expanding, group gatherings for this individual not to be taken up immediately)."*
- *"More practical suggestions like self-care, easier ways to manage in the home, ways to cope with chemo treatment. Possibility of keeping a memory book.... discussing memories with self and family/friends; listening to favourite pieces of music; looking at a book given on subject patient as talked about."*

Other responses refer to knowledge and skills gained through training that were used to signpost to resources, to support the individual in making informed choices and advance plans.

- *"Hospital resources - digital support possibilities, recommendations for appropriate reading matter"*
- *"Advance planning"*
- *"I have mentioned to his wife about the yellow folder and we talked about dropping one in for them to look at to open the discussion slowly"*

• Volunteer management support and supervision

The proposal for funding stipulated the resources in terms of project management and volunteer coordination at a time when there was existing Public Health Localities Team project support and further support from within the IESCCG. As the pilot project unfolded and there were different demands, the 0.4 FTE Project Manager post had to embrace both functions and provided first point of contact support to and management of the volunteers.

An accredited psychotherapist provided group supervision and support on a monthly basis. This was originally face-to-face at the Hollesley Practice and lasted two hours. With the onset of COVID, it moved to ZOOM and was reduced to one our due to the intensity of a ZOOM meeting and less contact with patients.

The importance of management and supervision will be discussed further in Chapter 5 by the psychotherapist engaged in the project.

The Compassionate Companions' Diary and Log was also an important mechanism to pick up issues that were emerging. One entry highlighted the emotional toll that volunteering both by the Project Manager and the Compassionate Companion.

"I found the call very overwhelming and wished I could do more to help and found myself getting very upset."

This was addressed with 1-2-1 support to the volunteer both by the Project Manager and the psychotherapist.

Similarly the Diary and Log enabled Compassionate Companions to express training needs, which again were discussed with the Project Manager and repeated within group supervision.

"Continuing training for being there for someone as they inch nearer towards their EOL days."

"Bereavement/grief training."

"I raised at group supervision my concerns about skills required to support someone with grief/bereavement and asked if further training on this was available."

The Diary and Log also asked Compassionate Companion to consider how they were considering their self-care. Whether the interaction was face to face or by telephone, responses were similar. It depended upon the individual Compassionate Companion's interests as to how this was approached; whether that be swimming, pilates, meditation, talking, walking, group supervision, peer support through Compassionate Companions or EOL Doula UK.

The use of reflective practice was encouraged and supported through the Diary and Log too. Compassionate Companions were always asked to think about how things could have been improved. Responses were monitored by the Project Manager and addressed as required.

"I think I could have improved things by asking for help sooner"

"A reduction of my stress levels through talking over with individual the issues and encouraging her to express whatever worries, concerns she has"

"I felt like I needed much more practical information"

An additional offer of 1-2-1 mentoring is in place through membership of EOL Doula UK, together with regular group peer support as part of a Regional EOL Doula UK group.

• Patient identification and matching

The process of patient identification was agreed at practice level utilising the Gold Standards Framework, patient coding for project purposes and updates onto the Patient Record.

The processing of matching a patient with a Compassionate Companion was agreed according to location, capacity and "soft intelligence" gathered by Dr Crockett, staff at the Peninsula Practice, and via multi-disciplinary team meetings with the hospice and community teams. The GP attended the first introductory meeting with a Compassionate Companion and the individual. It was always acknowledged this model may not be sustainable in the future. During the course of the pilot, within the data capture period nine patients of the Peninsula Practice were identified and matched.

Identification of patients and referral to a Compassionate Companion became increasingly difficult due to COVID. A number of steps were taken to address this:

- A Compassionate Companion telephone support offer was extended to all practices across the whole IESCCG. No patients took up this offer.
- The Project Manager met with the Strategic Lead of Macmillan Cancer Services at East Suffolk and North Essex NHS Foundation Trust to explore how the Compassionate Companions could become a resource in the community for the Care Navigators to refer geographic support network outside of the Peninsula Practice.
- The Project Manager met with the manager of Age Concern Colchester EOL Companion Volunteer programme to understand synergies and opportunities to generate referrals. The geography restrictions of the Pilot Compassionate Companions made this difficult.

Within the Compassionate Companion volunteer group there remains capacity for referrals as uptake has been confounded by COVID and some have expressed concern, whilst they are not "matched", they are losing confidence in their skills.

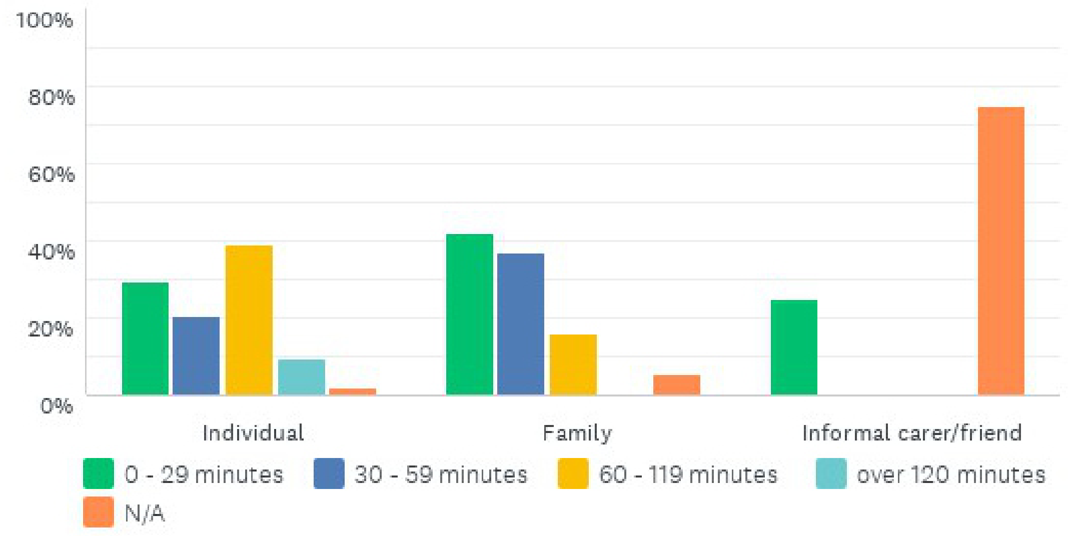
• Analysis of Compassionate Companion support

Face-to-Face Support

The pilot was set up primarily to offer and provide face-to-face support to patients identified by the Peninsula Practice. But of course, COVID, isolation and social distancing requirements from March 2020 had a significant impact on the way the project developed, as well as where and how interactions took place. At this point, there was a shift away from face-to-face interaction and contact was by telephone. (A separate survey documented this interaction see later).
The length of time spent each with the individual, family, and/or informal carer or friend was captured across time bands 0-29 minutes, 30-59 minutes and 60-119 minutes and over 120 minutes.

The cumulative data is shown here:

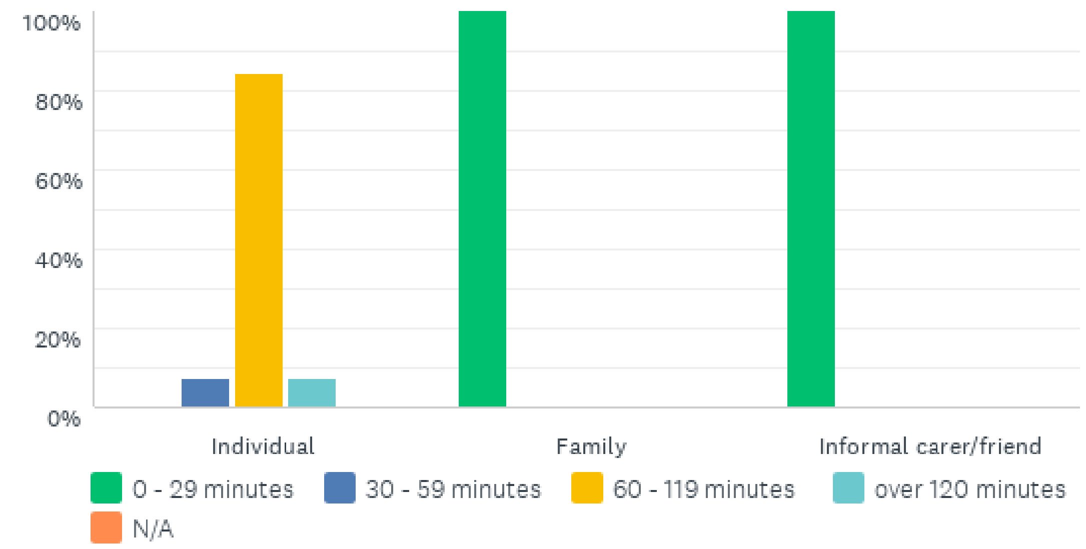
Q4 Please indicate the length of time spent with the individual, family and/or Informal carer/friend:



Because of the very different relationships and type of support being provided, an analysis at individual level shows a very different picture.

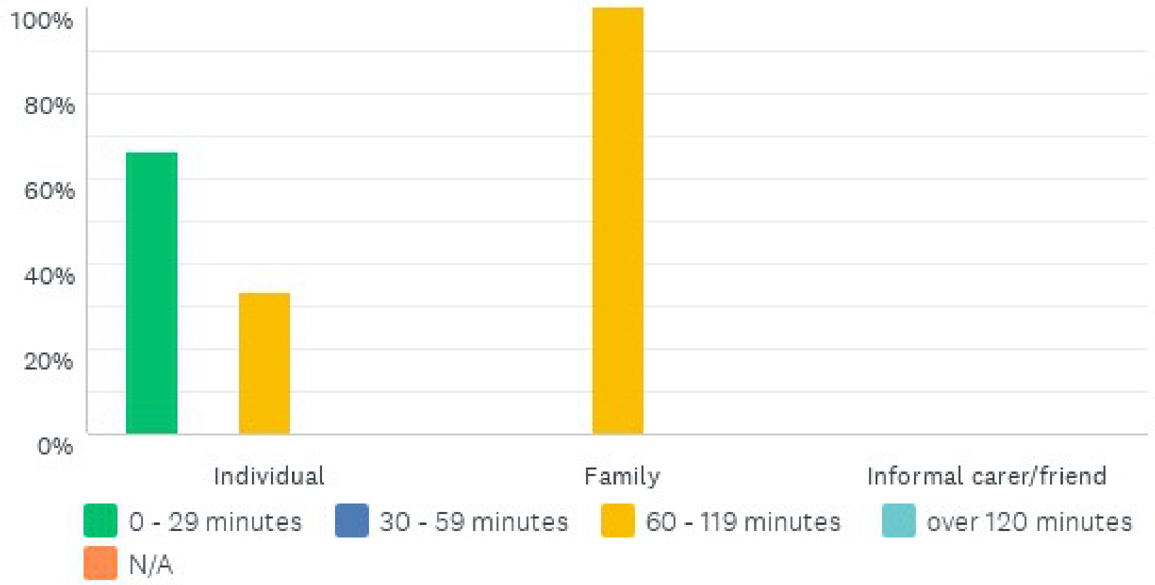
For example, one Compassionate Companion on average spent 1-2 hours with the individual each visit and up to 30 minutes with a family member or carer.

Q4 Please indicate the length of time spent with the individual, family and/or Informal carer/friend:



Another Compassionate Companion recorded visits of up to 1-2 hours with a family member or carer, with shorter interactions with the individual.

Q4 Please indicate the length of time spent with the individual, family and/or Informal carer/friend:



Whilst another Compassionate Companion recorded that almost 50% of her face-to-face interaction with the individual was between 1-2 hours and almost 50% exceed 2 hours, with there being no family or carer contact.

The data demonstrates a significant variation in the support provided by a Compassionate Companion that is always determined by individual needs. The relationships evolve, and the Compassionate Companion responds accordingly in a flexible, open manner in the best way possible to offer support to whoever requires it within that household. This occurs fluidly when the relationship is face to face and within the individual's home.

Not all face-to-face interaction exist in the household though, as only 68% of visits occurred in the home. Compassionate Companions, when able to meet, have often taken their own dogs along for a walk and talk and exercise, or gone to a café or restaurant, bringing a new and social environment to the individual. Other face-to-face interactions occurred during lockdown from a distance, the Compassionate Companion visiting after undertaking errands such as shopping and spending time talking from an open window.

Those compassionate conversations and the emotional support provided defines the role of a Compassionate Companion; they rarely provide practical support. Only in 7% of these face-to-face interactions did Compassionate Companions provide practical help or perform small tasks. When they did it was generally to make a cup of tea, but on some occasions, it included making a phone call on the individual's behalf to cancel an appointment or to request further support. A good number of the individuals already had a more appropriate network of support in place from family and good neighbours to provide practical assistance.

The type of conversations varied immensely. The Compassionate Companions described almost all of them as "befriending conversations". However importantly 60% of those same discussions also covered "difficult conversations between individual with family/carers" and 45% considered "unsaid conversations and unfinished business". Some quotes from Compassionate Companions are:

- *"Individual stated that she really enjoys having me as a Companion as she sometimes prefers to speak with someone outside the family about things she finds more awkward to approach with her adult children or friends."*
- *"Found common interests – like our love of India. Took my dog! Family members also have cancer and so lots of unsaid conversations at moment."*
- *"Now she is bereaved, we talked about her own end of life through cancer but also about normalising grief."*
- *"Individual is reticent about discussing her condition with her family as she does not want to upset them, although they accompany her to hospital appointments & care for her generally. She is opening up to me and talking a little more about living with her illness and how she likes having a companion with whom she can discuss certain issues."*
- *"Individual well able to express herself around difficulties with family conversations and completing unfinished business."*

Conversations more specifically in relation to elements of advance planning and the 'My Care Wishes' folder have been harder to establish and have depended on the length of relationship and the stage of the individual's illness.

The training provided by Living Well Dying Well nurtures the use of reflective practice and the questionnaire supported this approach for the benefit of the volunteer as much as for the learning from the pilot project, asking;

- What went well?
- What did not go so well?
- What could be improved?

Some Compassionate Companions identified the first introductory meeting with the patient, accompanied by the GP, as something that 'went well'.

- *"Friendly meeting, lots of space and time to chat. Dr Crockett was very compassionate."*
- *"It felt like a calm, open discussion. Dr Lindsey Crockett was compassionate and gently introduced the idea of how to involve a Com Com."*
- *"Atmosphere relaxed informative and open. Dr Crockett professionalism outstanding. Listening and observing."*
- *"The individual was open and ready to receive a 'Companion' and able to state how visits should proceed on her own terms. Friendly, willing and warm-hearted."*

Other things that the Compassionate Companion perceived to have "went well" relate to the building of rapport, open conversation, and allowing space to talk which is clearly easier over a longer face-to-face interaction. There is clear positive impact here on reducing loneliness and isolation too.

- *"We took a route on dog walk that she had not done for years so our outing really became a social trip."*
- *"Positive meeting found common ground re artistic interests- sea glass jewellery. They liked my honesty about why I was doing this."*
- *"Helped to reduce isolation - and loneliness - change of scenery and company provided other than own home and the hospital where her husband is."*

- *"Individual was feeling in good spirits during my visit and reminisced about her past life experiences and we shared remembrances of lifestyles and available foods, fashions etc. She also took the opportunity to talk about her concerns for some family members."*
- *"Intimate conversation around feelings about approaching the unknown end of life. Planting two acorns in a plant pot together which had been sent to Com Coms/Doulas from Living Well Dying Well team which will later, at individual's request, be transplanted into the woods near to her eldest daughter's house."*
- *"Ability and space for individual to discuss feelings, hopes, fears about decline in health, facing an unknown future. Individual's enthusiasm for life and making crafts, knitting."*

- *"Able to discuss how she's feeling on an emotional & physical level - on tender-hooks re: awaiting a phone conversation with a consultant about procedure or not of chemo-therapy treatment."*
- *"Ability for individual to feel free to talk about particular concerns around her present situation thus far in chemo treatment and her state of health in all respects. Individual had sewn me a small heart cushion as 'a keepsake."*
- *"Our open & honest conversations around individual's medical care and her feelings & thoughts about this situation. Individual had baked a Victoria sponge cake of which she was proud and offered me a slice with a cup of tea. She is now commencing with knitting socks!"*

- *"Individual was pleased to meet with me again in person and shared a lot of her feelings and asked me to share some favourite music with her. I invited her to show me around her garden so that we could conduct most of our meeting in the open air."*

The Compassionate Companions made the following comments relating to thing they perceived did not go so well:

- *"Patient did not wish to have Compassionate Companion given to her as she apparently already has it."*
- *"I had been asked to meet Dr Crockett in layby rather than be given address… not such good idea in hindsight, in terms of phone signal and dark and not finding each other, which then made us late."*
- *"She did not want to discuss inevitable outcome of her ongoing illness & all that surrounds the dying process."*
- *"Individual reluctant to discuss in detail the more practical issues around EOL as I suspect that because not in pain she believes things are improving and therefore tends to be a little dismissive of the need to."*

Many other comments reflect the difficulties to offering support during lockdown:

- *"Conversation restricted from distance and open window."*

Other comments relate to specific interactions and join up with the GP surgery:

- *"He seemed a bit poorly and I was concerned enough to phone GP surgery to explain I was a Compassionate Companion and matched with this man but I had not been given anything more than his first name (no other info) and two separate staff members put me on hold not seeming to know anything about Compassionate Companions or what I was doing. I gave up and contacted Dr Crockett directly."*
- *"Individual did not like being given Yellow Folder at end of my visit."*

Reflections from the Compassionate Companion about what they felt could be improved very often related to seeking a "better conversation".
This is reference to either lockdown preventing quality face-to-face contact or the contact being in early stages and a recognition that better conversation might be achieved once greater trust and rapport is established

Other comments related to project set up and communication needs, or include observations about the "system" rather than project per se, in particular issues regarding joined-up or follow-up care.

- *"I need to be provided with patient DOB and surname. Practice needs to be better aware of Compassionate Companion roles."*
- *"Further ongoing communication between all who are involved in this individual's health-care plans."*
- *"Joint communications between the carers/nurses/hospice/surgery & hospital."*
- *"Surgery communications re: medication."*
- *"More visits and 'tracking' of this patient's increasing medical and comfort needs."*

Telephone Contact

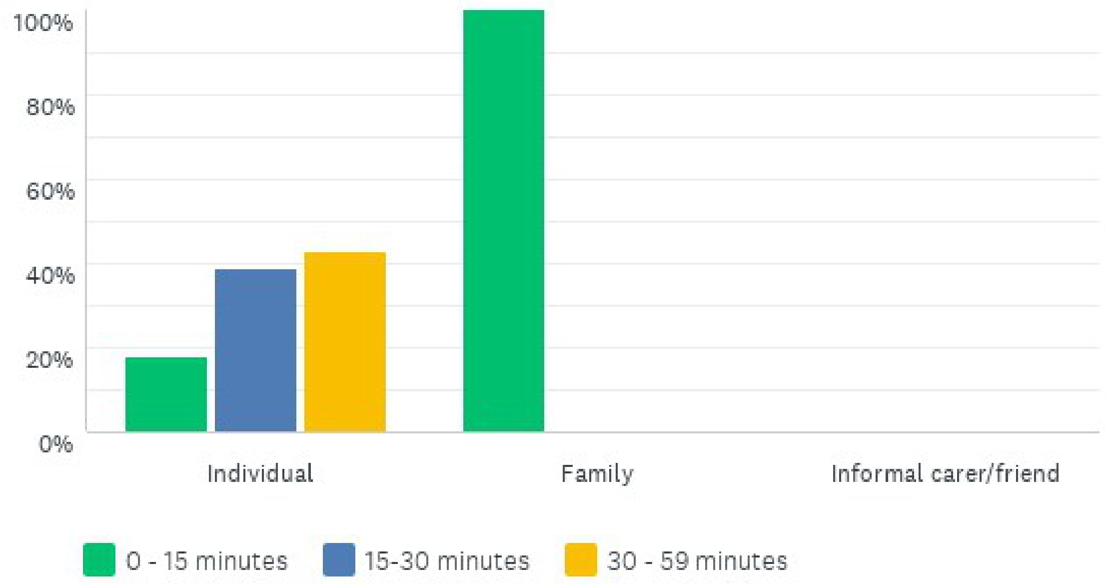
From March 2020 and during the COVID pandemic it became a necessity to maintain contact by phone, rather than face-to-face contact.

From March to December, when we collected data on a separate Survey Monkey tool, a total of 79 entries were made. We know though this is not complete in that contact from one Compassionate Companion has not been fully recorded. It should also be noted that a small number of these shorter phone contacts are actually a series of communications by text: still an important means of having a conversation, but not by voice. Equally, a very large number of text conversations (not one off messages) have not been recorded.

Of these 79 telephone calls, just two were to family members. All the rest were with the individual.

- 14 calls were short between 0-15 minutes
- 30 calls were 15-20 mins long
- 33 calls lasted 30-59 mins

Q4 Please indicate the length of time spent with the individual, family and/or Informal carer/friend:



Again, the nature of the contact varies significantly according to the type of support being provided. Some of these were short calls to arrange a face-to-face meeting later or simply for the purposes of providing practical support, to discuss items for a shopping trip. Other calls were lengthy, providing deep emotional support.

One individual had only just been introduced when lockdown commenced and the relationship of support became quickly focussed upon shopping and running errands, rather like a Good Neighbour. This meant that 80% of that Com Coms telephone (or text) contact was short less than 15mins in order to communicate shopping needs. It was then followed up with a similar length interaction on delivery of goods from an open window.

In comparison, a different individual already had an established face-to-face relationship that had to change to telephone. During March to December, 39 calls were made, all to the individual with the exception of one short call to family. The majority of these lasted 30-59 mins and had a deeper level of communication, and support provided by a Compassionate Companion/Doula type role.

Meanwhile another Compassionate Companion had commenced support to an Individual by providing a safe place to talk initially about her husband's illness and then his death, before later being able to focus upon the individual's EOL journey. Many of these calls were "holding space", and have gone a long way to reduce the individual's loneliness and isolation, whilst also providing bereavement support. On a number of occasions the individual has called in a distressed state and the call has helped calm the individual.

Every telephone call was considered by the Compassionate Companion to have:
- Successfully created an environment that was respectful and unhurried
- Built some trust and rapport in order to have a conversation
- And primarily provided befriending and companionship

In addition:
- 60% of those calls also were perceived as providing an opportunity to talk about how to have any difficult conversations between individual and family/carer about future wishes
- 45% of those calls also were perceived as providing an opportunity to help the individual to consider and /or deal with unsaid conversations/unfinished business

The comments logged in relation to these calls can be clustered in this way.
(Note: This is just a selection of comments)

Reducing Loneliness and Isolation

- *"Feeling isolated, trapped ad missing close friends- offered support and space to listen/sound out."*
- *"Feeling very alone and isolated and especially concerned about husbands deteriorating health."*

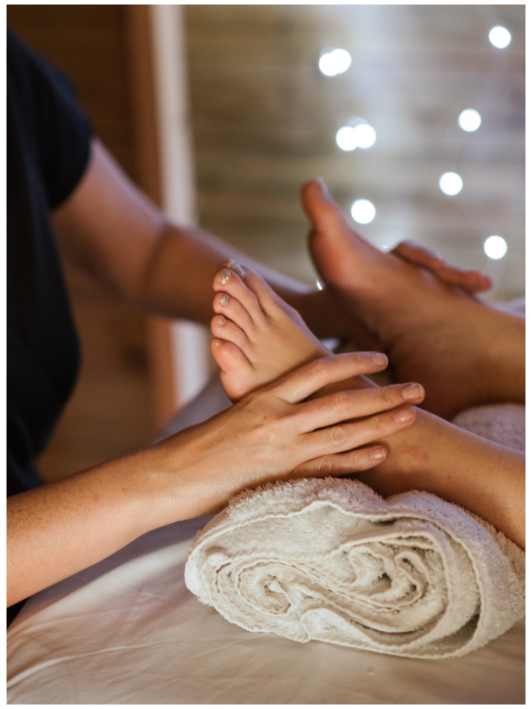
Providing Emotional Support/Holding Space/Listening:

- *"She rang me very upset - I provided a safe space for her to talk about her fears."*
- *"She was in a lot of pain - I offered support and reassurance and said I would ring hospice to see if respite was available."*
- *"She rang me in a distressed state - I was able to calm and reassure."*
- *"Emotional support - it was her husband's funeral today."*
- *"She phoned me to tell me her husband had died- I provided space and a comforting ear ."*

- *"Able to listen, empathise and guide during individual's need to explore feelings around the continuing decisions she has to make - with the aid of family members - about further chemotherapy treatment."*
- *"Able to provide some guidance on how to face fears of EOL and medication to combat pain etc."*
- *"Listening to individual's difficulties in not feeling able to attend chemo-therapy treatment due to physical issues and making suggestions as to how she could obtain some professional and family support around this issue."*
- *"Talking through the individual's wishes for EOL in terms of where to be at end other than at home. Listening skills, guiding, empathising whilst individual explores with me various options concerned with terminal illness, such as amount of care needed, medication regime, number of chemo-treatments etc."*
- *"Making a space for the individual, with the occasional prompting by inquiry, to explore her thoughts and feelings about preparing for EOL in all kinds of ways, e.g. spiritually, physically, mentally & emotionally."*

- *"Listening skills, upholding views, ways of coping, frustrations of individual, esp. when she is at hospital receiving chemo in room alone instead of being with others and enjoying a chat with those patients she has got to know... alone, it seems like a long day to her. Dealing with euphoric mood of individual, plus her worries about struggles to cope, especially when alone at night."*
- *"Listening to person talk about her family - past and present, helping her to express feelings around memories of her past life."*
- *"My companion has had to face her mortality due to the death of her husband and her current prognosis yet there is a huge fear around it."*

Signposting and Consideration of Alternative Ways to Approach Pain Management



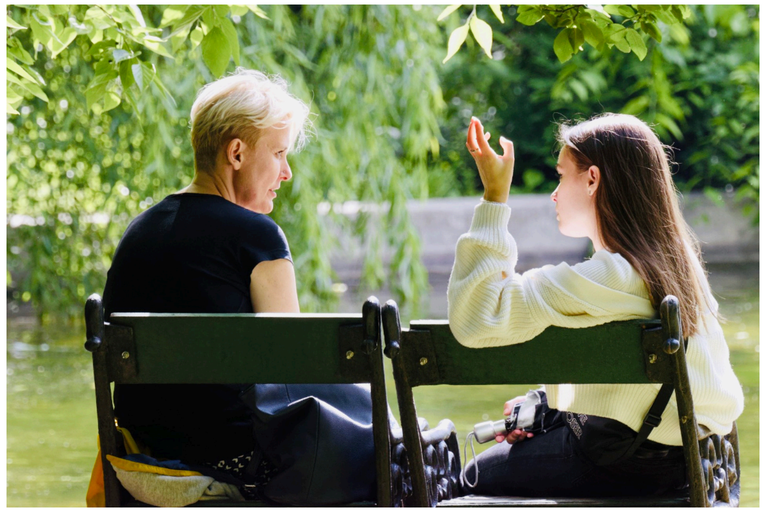
- *"We were able to share knowledge about the creative and therapeutic practices available."*
- *"Signpost to resources when/if needed in terms of treatment, support etc."*
- *"Introducing different suggestions as to how to cope with the continuous side-effects of illness either alone or with the support of family members or outside medical care."*
- *"Support regarding pain management in practical terms - feeling connected so reducing isolation/loneliness - normalising feelings- talking about her fears."*
- *"We chatted about her options re cancer and pain management - I offered support and listening ear."*
- *"Able to suggest possibilities of looking at grief - was a very productive conversation, very open and honest."*

Advocacy Support

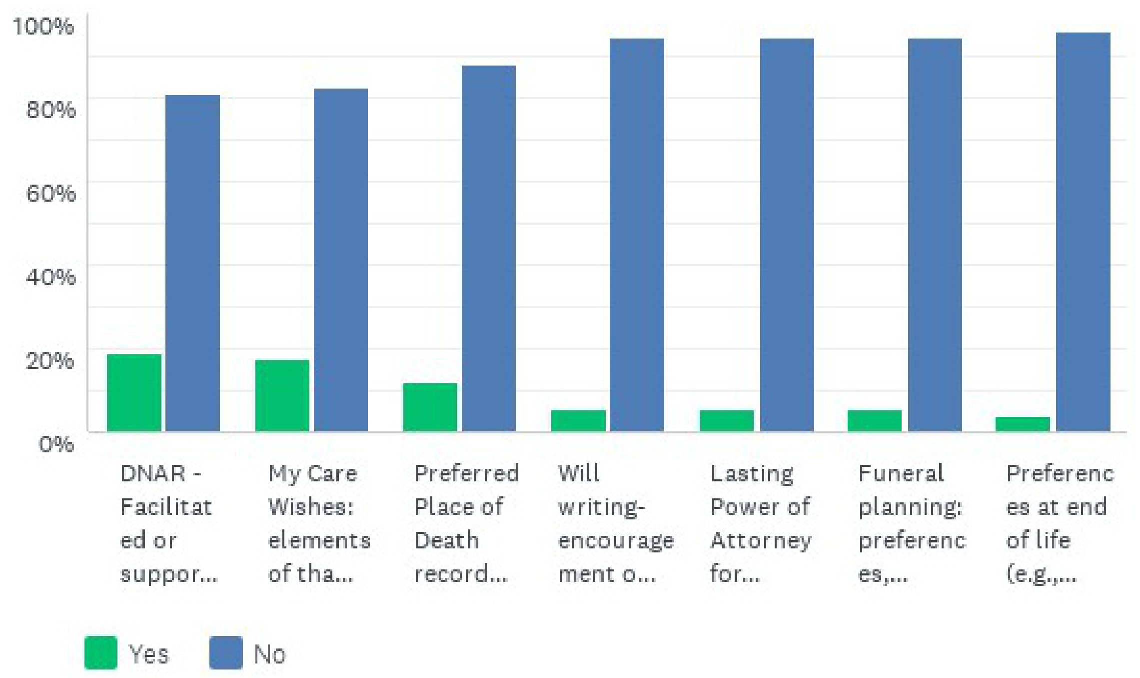
- *"Encouragement to individual to state her opinions/needs about her health treatment to those who can support her; giving herself a voice."*
- *"Introduced various channels through which Individual, as a terminally ill patient, can have her voice heard."*
- *"Possibility of what to say and how to approach professionals dealing with individual's long-term illness."*

Facilitating Conversation with Family

- *"Helping to resolve family conflict and suggesting ways to relax and unwind from stress caused by such."*
- *"Giving guidance and verbal support about how to approach family members and cope with their varying ways of responding to the individual's illness."*
- *"Suggestions/encouragement to this independently minded individual to ask for extra help: care, home help, consultants, local GP when needed as it is during this vulnerable time."*



These telephone calls overall only picked up on Advance planning conversations in a minimal way.



Q7 During your call, were any of the following discussed?

However, one Compassionate Companion did have significantly more of these Advance Planning conversations on the phone because of the state of the individual's health and their longer standing relationship.

As in the face-to-face tool, the Compassionate Companions were similarly encouraged to utilise reflective practice and record thoughts about

- What went well?
- What did not go so well?
- What could be improved?

As usual, this varied according to nature of relationship.

Compassionate Companions reflected that it was good that the individual was willing to engage on the phone, and very often would record how through a phone call they had still been able to have an open honest conversation, build rapport and trust, provide a safe space, a listening ear, and offer suggestions.

Predominantly, where the relationship was less developed and more focussed upon running errands, the Compassionate Companion reflected that they were less successful at engaging as a diploma level trained doula and unable to utilise skills and share knowledge the training had given her. This was probably due to the COVID situation frustrating the development of a deeper level of support, although some evidence points to the individual not being fully aware or understanding the potential Compassionate Companion offer, or actually not requiring it.

- *"Limited contact due to COVID and possibly individual and partner not requiring the available support of a Compassionate Companion/Doula."*

When asked what could be improved, there were a range of responses including:

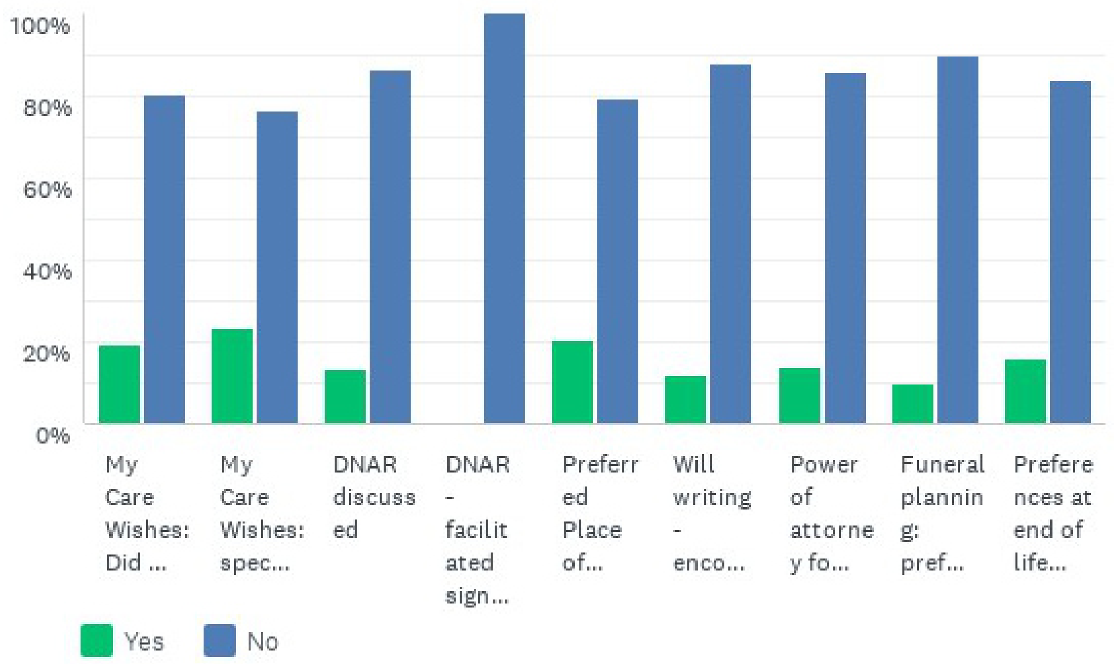
- A desire to get back to face-to-face meetings:
    - *"Face-to-face discussion."*
    - *"To return to home visits after lock-down as phone calls no substitute for talking face to face with a person who is experiencing a whole range of emotions at this sad time."*
    - *"Spending actual time together, but she is shielded so this won't happen for a while."*
- Acknowledgement that this person is not ready to talk about illness or EOL and a desire to undertake the real and trained role of Compassionate Companion rather than Good Neighbour/errand runner:
    - *"I would have liked to have got to know her better and put my skills and training to diploma level into practice, providing real support to them both."*
    - *"Patient is not ready to speak about death and dying."*
    - *"Getting individual to somehow explore her feelings around the reality of facing and preparing for the end of her life, since she is always determined to be on a positive, high mood when talking on the phone to me."*

- *"Improvements to the continuity of care, support of/access to GP practice/medications"*
- *"Having more ability to 'fix' practical issues for individual, such as receiving correct meds at time when they are needed."*
- *"More input from local GP surgery & doctor even if every so often."*
- *"More ease of communication between all this individual's medical care teams, locally and at hospital level in the individual's opinion."*
- *"Provision of medications delivered at appropriate times and communication with surgery staff plus further GP interest/calls in patient's ongoing progress with their terminal illness."*

2c) Peninsula Practice patients at end of life are better informed and supported to make end of life choices, record them and implement them

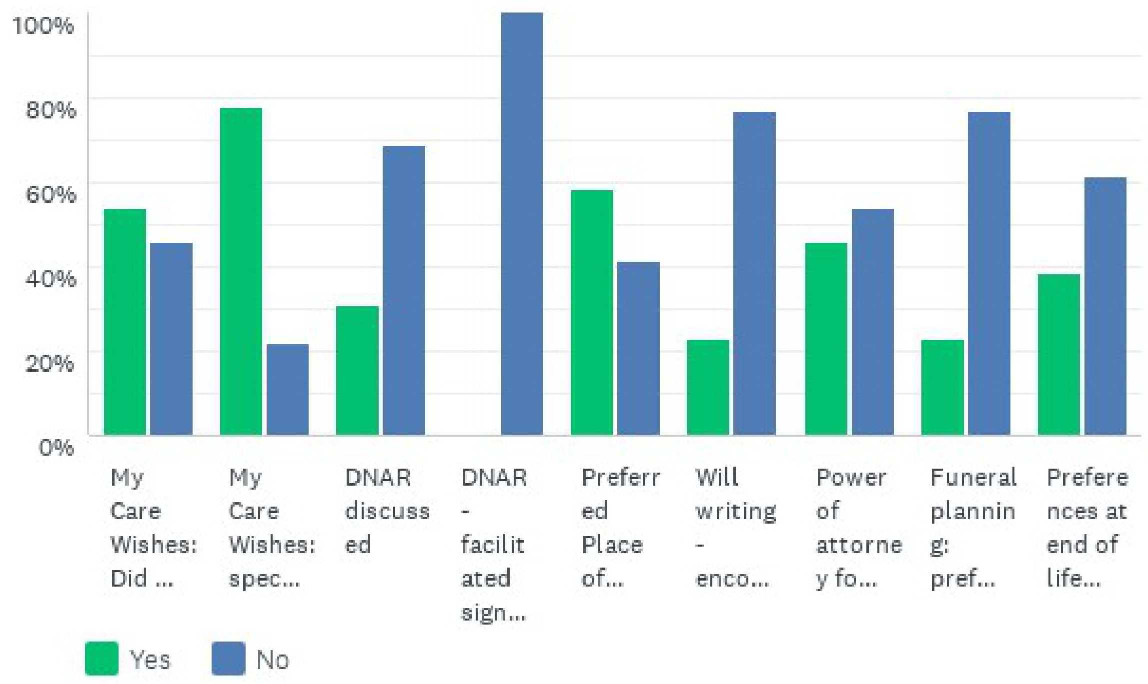
It proved difficult to get the referred patients to discuss end of life choices and record them and when the My Care Wishes Folder was completed with a referred patient, it was done so by the GP alone without engagement with the relevant Compassionate Companion as a preliminary or complementary conversation aide. Compassionate Companions found the Yellow Folder "user unfriendly" and prefer some of the advanced planning tools elsewhere.
Conversations more specifically in relation to elements of advance planning and the 'My Care Wishes' folder have depended on the length of relationship and the stage of the individual's illness. Cumulative data shows:

Q13 During your visit, were any of the following discussed?



In the case of the Compassionate Companion who has been supporting someone for 12 months now, the relationship of trust and openness is strong and the individual's condition has deteriorated significantly over time, making such conversations more relevant and common, as demonstrated below:

Q13 During your visit, were any of the following discussed?



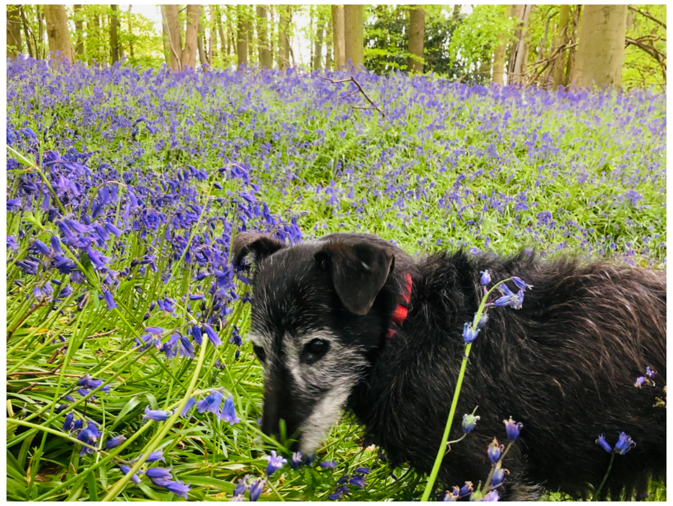
The Compassionate Companions were asked if any changes had occurred within the 'My Care Wishes' folder since the last visit. This happened on just one occasion, verbally.

Compassionate Companions were encouraged to discuss the challenges to and facilitation of "Talking about End of Life", both within this evaluation tool but also regularly within group supervision and peer support sessions.

- *"This individual is well at present so that these above issues are not right now relevant."*
- *"Individual was open to discussing various preferences as to how and where she wishes to die, but for the present, she prefers to see how she will respond to the palliative treatment she's having and feels brighter right now."*
- *"My companion does not really see herself as ill and is focussing on having chemo to shrink the cancer, therefore end of life chat does not seem appropriate to her right now."*
- *"The individual being visited by me is fiercely independent, intelligent and is well aware herself of how and where she wants to die (except that she does not wish to know exactly how long she has before she dies). She has therefore put most necessary plans into place. She is very willing to discuss all other aspects of preparing to have as pain-free death as is going to be possible in the circumstances."*
- *"As patient individual had hypoglycaemia episode previous week when both daughters were with her and they were able to call ambulance and have her taken to hospital. She is well aware that had they not been there she would probably have died, so a conversation around that situation was had between individual & myself."*
- *"Discussions around what next decisions to make re: treatment and possibility of hearing bad news from radiologist next week and how to prepare for whatever outcome. Individual very unsure and anxious about what to expect, and we were able to work through some of those fears in our conversation during my visit."*

One individual declined always to talk about her life limiting illness, preparations for end of life, or indeed to find out what the support of a Compassionate Companion could offer in this respect. Her connection to a Compassionate Companions was simply to have some company and primarily with someone who owned a dog, so they could go on dog walks together.

Two different Compassionate Companions connected with this individual with their dogs but the individual decided not to continue with this relationship.



Another Compassionate Companion, whose relationship became primarily focused upon providing shopping and running errands as a Good Neighbour, faced similar challenges.

Whilst all of the above is important and valid, it should be recognised that it can cause some frustration or self-doubt amongst Compassionate Companions. These concerns were picked up by supervision and peer support.

The pilot project did not just rely on the role of the Compassionate Companion to make Peninsula Practice patients better informed and supported to make end of life choices, record and implement them. Activity was broader and included:

- Links to specific tools and information are provided on our website https://www.compassionate-communities.co.uk/resources

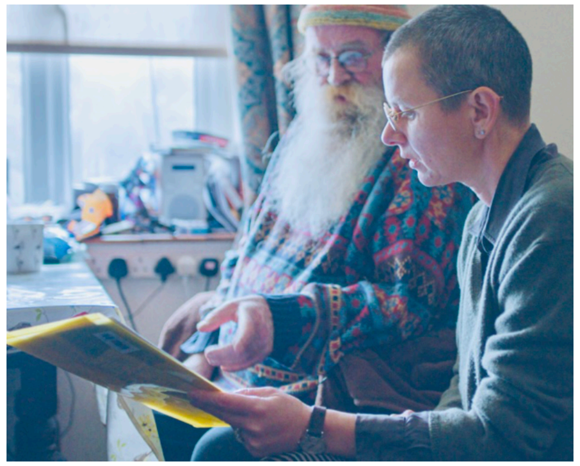
- My Wishes proposal was developed and shared with EOL Programme Board 28-07-2020, it was supported in principle but no funding yet sourced

- Ways to initially engage people in advanced planning with small workshops focussed on Digital Legacy and creating digital EOL champions were explored but not delivered because of COVID

Compassionate Companions Film

A Film was made to:

- Encourage new volunteers to come forward to join as a companion to enrich the Compassionate Communities
- Give confidence to volunteers/family members/carers to have difficult conversations regarding end of life choices
- Enable people within communities to recognise their abilities in supporting each other particularly with non-medical support at end of life
- Describe by gentle conversations advance decisions/ resuscitation/power of attorney etc



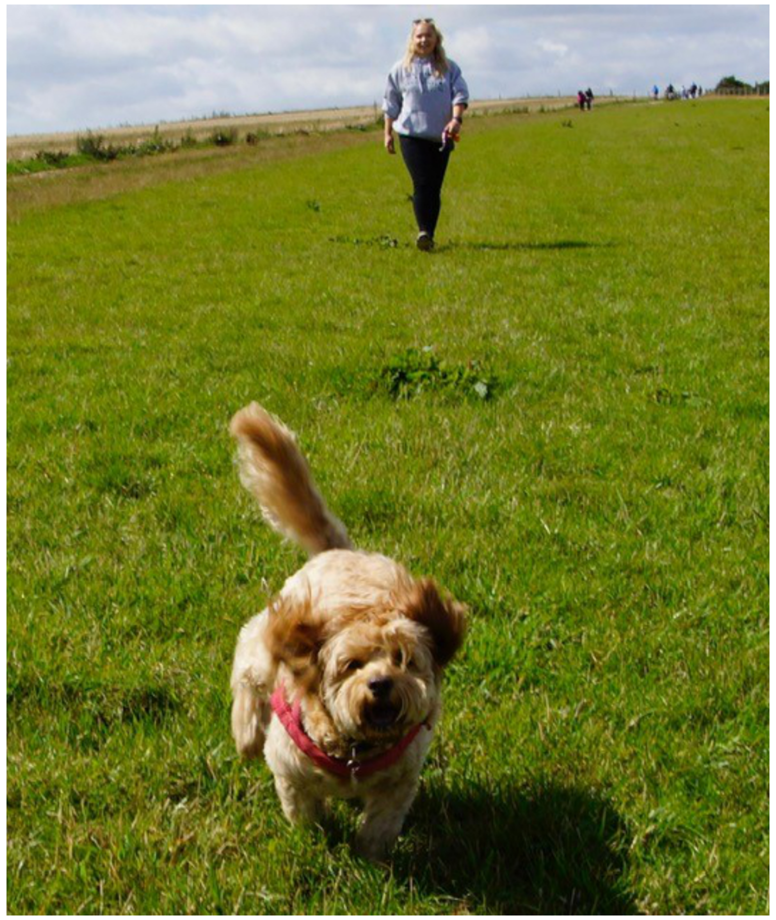
2d) Family and Informal carers are more resilient to maintain an end of life caring role and have increased knowledge of EOL care key principles, practice and processes

The Compassionate Companion played a key role in enabling family members or carers to do other things and get some respite. Importantly, in 33% of face-to-face interactions the Compassionate Companion recorded this as an impact of their visit. Of course, again, this cumulative data disguises the very different relationships the Compassionate Companions had.

Whilst one Compassionate Companion said that 93% of her visits enabled such respite, another was never able to report doing this, as she was supporting someone who lived alone without any family or care support to relieve.

Compassionate Companions described what they had enabled family and carers to do:

- *"Family able to carry on their own tasks at their individual homes."*
- *"Offered to sit with individual so wife could get respite."*
- *"Daughter and son enabled to attend their workplaces respectively."*
- *"Family who normally cares each day for patient was able to go to visit her son away at University."*
- *"Daughter able to have respite from caring role and to attend to own work."*
- *"Daughter able to take individual's dog for a walk."*



Variations in Role According to Face to Face or Telephone Support

Whilst not originally intended to be tested as part of this Pilot, COVID forced the project to provide solely telephone support for a period of time. It is important therefore to consider whether the type of contact made and sustained affected the role of the Compassionate Companion in any way.

The analysis of both questionnaire responses suggests that any variations in role between Compassionate Companions never emerged from the way contact was made. The variation in type of support being provided, the depth of conversation and emotional support, always resulted from the individual's needs and wishes.

Companions and individuals were able to adapt their approach and method of contact accordingly to continue support safely during the Pandemic. The Compassionate Companions must be given credit for their willingness to adapt their volunteering to operate within the COVID situation, and their commitment to sustain the support being previously provided to individuals.

There were some frustrations of course as expressed in some of the comments, but fundamentally there is evidence of ongoing, in depth and timely emotional support, being provided over the telephone too.

1e) Communities have networks of support for End of Life

The Compassionate Companion has a key role in encouraging and supporting individuals to map out social and support networks, identifying opportunities that match the interests or needs of the individual, and helping them to access these opportunities.

Whilst there are social prescribers/community connectors attached to the medical practice who can also do this, the following extract documents the significant role Compassionate Companions play here.

Compassionate Companions were asked to describe any new connections made with wider social support or networks for the patient, family/carer and signposting to community assets:

- *"Did a mapping exercise to note all his family members and community support networks/friends."*
- *"Meditation practice online for patient to engage with."*
- *"Signposting to Good Neighbour scheme."*
- *"Talked about wider befriending support networks available."*
- *"Suggestions on how to access surgery staff for medication on appropriate delivery days."*
- *"Carer, chiropodist, volunteer dog walkers have all been resourced by individual."*

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- *"Discussed social media and ways of communicating that way. looked at photos/music storage and listened to/looked at together. Discussed seeing friends in her own home."*
- *"Finding appropriate Internet links - e.g. audio books, library/music preferences. Family carers already have their own resources that they use as a support for themselves."*
- *"Discussed over sixties club near individual's home - wants to attend but a little anxious – said I'd accompany if right timing or suggested she could perhaps go with daughter, which individual thought was good idea."*
- *"Chatted about hospice follow up groups (husband just died)."*
- *"Several local community connections such as social club, WI etc. discussed as possibilities of getting to know people socially."*
- *"Suggestions on how to access surgery staff for medication on appropriate delivery days."*
- *"Discussions on best people to approach re: ordering & receiving (on time) appropriate medications."*
- *"Signposting to carer/nurse networks."*

Work Stream 2

Improving Death Literacy

3a) Undertaking public engagement activity to provide information and resources

A Creative Arts sub group undertook a review of activity locally, nationally and internationally and began scoping opportunities for local events and engagement activity.

Membership of the Creative Arts sub group was fluid in order to enable our volunteers and professionals who had completed the training course to contribute their skills and time accordingly as opportunities arose.

The first event coincided with Dying Matters Week in May 2019, and a number of information stands were set up in the Atrium at Endeavour House, Ipswich. Compassionate Companion volunteers attended alongside representatives from CRUSE, Marie Curie and St Elizabeth Hospice, with the aim of engaging with employees of the organisations working from Endeavour House in conversations about death and dying. There was music playing to encourage conversation about funeral planning, and a full size coffin to decorate alongside other factual guides.

A survey monkey questionnaire was circulated to employees the following day to assess their views and whether the event had stimulate conversation afterwards with family friends and colleagues.

In September 2019, a similar engagement activity was undertaken in Hollesley Village Hall when over 400 patients arrived to get their flu vaccinations.

The Project Manager and Compassionate Companions attended the East Suffolk Partnership Annual Conference at Trinity Park in November 2019 to engage with its 100 attendees.

In February 2020, Compassionate Companions and the East Suffolk Council Communities Team set up an open information event at Woodbridge Library.

The Project Manager met with representatives of five local Good Neighbour Schemes and the Development Manager to explore ways of working together to complement skills and volunteer time to best support people in our communities. Other Compassionate Companions spread the word about the project at "Meet Up Mondays" community events in Alderton and Butley.

The Compassionate Companions scoped and scheduled a series of "Death Cafés" at the Rendlesham Boardwalk Café. The first was delivered at the end of February 2020, the remainder were cancelled due to the pandemic.


Compassionate Communities added an **event**.
19 February at 11:23 ·

SAT, 29 FEB
The Art of Living and Dying Well
Boardwalk - Rendlesham · Rendlesham, Woodbridge

The group investigated turning these into online ZOOM Death Cafés and in doing so participated in numerous online Death Cafés occurring in England and overseas. The engagement and cascading of information and shared learning was good, but it was decided that, as there were so many opportunities for people to access these online events, the local project would not set up their own online Death Cafés.Other engagement activity was planned at the following events but cancelled due to the pandemic.

- Art for Cure –Glemham Hall
- Glebe House Care Home
- Butley Craft Fayre
- Rendlesham Country Fayre
- Alderton Country Show

The project partnered with Snape Maltings, working together to find ways to use a real energy and alignment of shared aims to find ways to use the creative arts both to support people approaching end of life, and to improve death literacy at every stage of life. For Snape Maltings this was particularly in relation to music. A key high profile event was planned for delivery on October 31 2020 at Snape Maltings. Activity on the day would include a Q and A session with a panel of prominent speakers and other workshops and information sessions that embraced poetry, singing, drumming, drama, storytelling, film, sand mandalas, sand jars, memory boxes, advance plans, digital literacy.

Unfortunately this event too was cancelled due to the pandemic. There remains an ongoing commitment from Snape Maltings and contacts, locally and nationally, to revisit this activity when it is possible. Whilst we know this will be outside of the initial project timelines, the project hopes to find ways to progress this, working also with the Regional Group of EOL Doula UK. The funding allocated to all this work has been ring-fenced so this can happen at a suitable time in the future.

With the diploma training and ongoing membership of EOL Doula UK, new ideas and fresh opportunities are emerging to work with other creative doulas nationally.

We were keen to learn from Doula colleagues who organise an annual "Pushing Up Daisies" week in Northern England, to compare and share ideas of how to move forward in light of the pandemic and social distancing. To inform thinking and networking, the Project Manager and Compassionate Companions engaged in the Good Grief Festival, a virtual event at the end of October 2020 (originally planned as a festival in May).

3b) Equipping children and families with necessary information and tools

Some members of the Creative Arts Group took responsibility for exploring ways to engage with children and their families. The Willow Project was scoped as part of activity to reduce the stigma attached to end of life and improve death literacy through the creative arts.

The project was organised to run in Sandlings Primary School, Sutton Heath Childcare Centre, Woodbridge and Sutton Heath Children's Centre from March 23, 2020. At the time, there was 80 children at the school, 90% of whom were in military families. Sadly, delivery was cancelled one week before the start date because of the pandemic. There remains a commitment to deliver this project and the funding allocated to it has been ring-fenced so this can happen at a suitable time in the future.

The project was designed to work with local professionals, craftsmen and community members (all DBS checked) including:

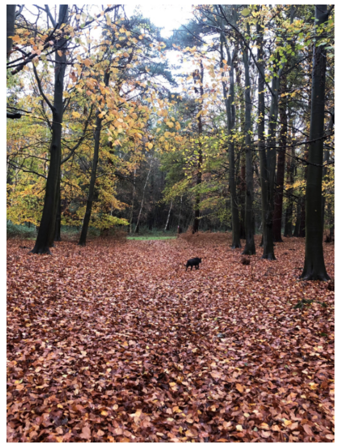
- A willow artist to construct a space out of willow where people can go to reflect, honour and remember.
- A wood sculptor carpenter to create a reflective bench and sculpted mole and badger statues
- A writer, story teller and crafter, drama therapist

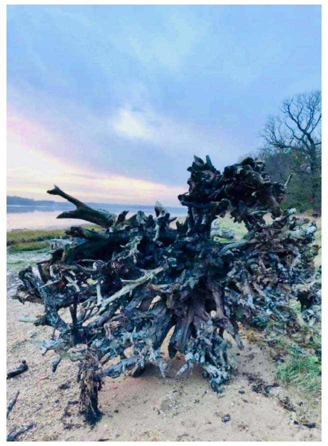
Alongside the construction, other techniques to explore these issues and feelings included:

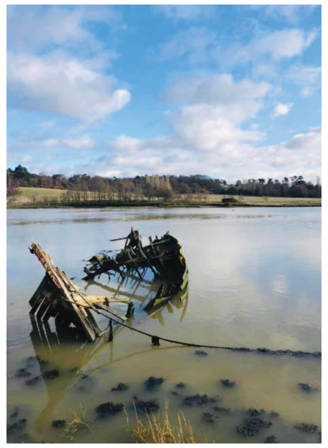
- Telling stories that prompt remembering that gifts are left behind, how the memory of a person or creature can live on
- Writing in honour and exploring emotions through haiku and nature
- Using sand creatures with different layered sand representing part of the memory of the person or animal that has died
- Making wishes /blessings for the person or animal to be hung on a memory tree and a line to blow in the wind
- Making dream catchers
- Creating an arbour possibly to act as an entrance to the special space
- A celebratory opening of the spaces: to invite the press to raise awareness of the compassionate communities project, to share favourite recipes/drinks possibly from Grandparents or Great Grandparents and possibly a tea ceremony with a candlelit mindful (no speaking) procession to the official opening.
- An exhibition at the key event in Snape Maltings later in the year

In addition, it was agreed to deliver a project in two other primary schools led by St Elizabeth Hospice and in conjunction with two of the Compassionate Companions. This project was in development when the pandemic prevented delivery. Again, there remains a commitment to deliver this project and the funding allocated to it has been ring-fenced so this can happen at a suitable time in the future.

The project was designed to work with Year 6 pupils over a six week programme, one half day in school. It included story reading and art activity linked to the stories; a beach or forest scavenge to gather materials to build 'creatures' with a focus on life cycles.







The intended storybooks were:

The Strong Little Tree – Helen Peacock - *teaches children about the life cycle of an oak tree, something they can then go out and observe for themselves in the wild. It is a gentle way to talk to children about the cycle of life and death.*

The Memory Tree – Britta Teckentrup - *a picture book to help children celebrate the memories left behind when a loved one dies.* It would end with and exhibition and Tea Party with 'Signposting' information for parents and a library list.

3c) Providing Information and Resources Onlines

The Compassionate Communities Website

The Compassionate Communities website was developed and launched in May 2020. It received positive feedback and in particular from Julian Abel (Compassionate Communities UK).

It has generated enquiries from other related programmes of work across the UK, joining up professionals developing their own compassionate communities locally. It has proved a useful resource for our Compassionate Companions too.

You can view the website at:

https://www.compassionate-communities.co.uk/

The website is designed to provide:

- Local project information about what a Compassionate Companion can do to support someone approaching End Of Life, information about local events, workshops and activity to improve death literacy and how to get in touch.
- A broader information base to make it easier to have difficult conversations about death and dying, so that people are better informed and able to make choices and decisions, and record them. This includes suggestions on how to start a conversation and what to cover, with plenty of resources to help you set out your wishes and support advance planning. The project did not seek to create new resources but to promote the already broad offer of resources that exists nationally, recognising individual choice about using online tools or hard copy documents

As part of its launch to coincide with Dying Matters Week in 2020, it encouraged people to participate in a five-day challenge to consider how they can best live a good life as well as best prepare for their own death or the death of a loved one. Activities as part of the challenge included choosing your funeral playlist, and finding creative ways to express grief, capturing family memories and creating a 'bucket list' of things one would like to accomplish before death. It was promoted by engagement activity using social media with other partners and key contacts locally and nationally.

Linking to Existing and New Platforms

The Project Manager looked at ways to initially engage people in advance planning with small workshops focussed on Digital Legacy, as this seemed a softer easier way to start conversations during the start of the pandemic. For example, encouraging people who, without social contact, were being forced to use social media and online conversations in way that they had not before. Opening up conversations about protecting their online photos, messages, and their social media presence after death seemed topical and important.

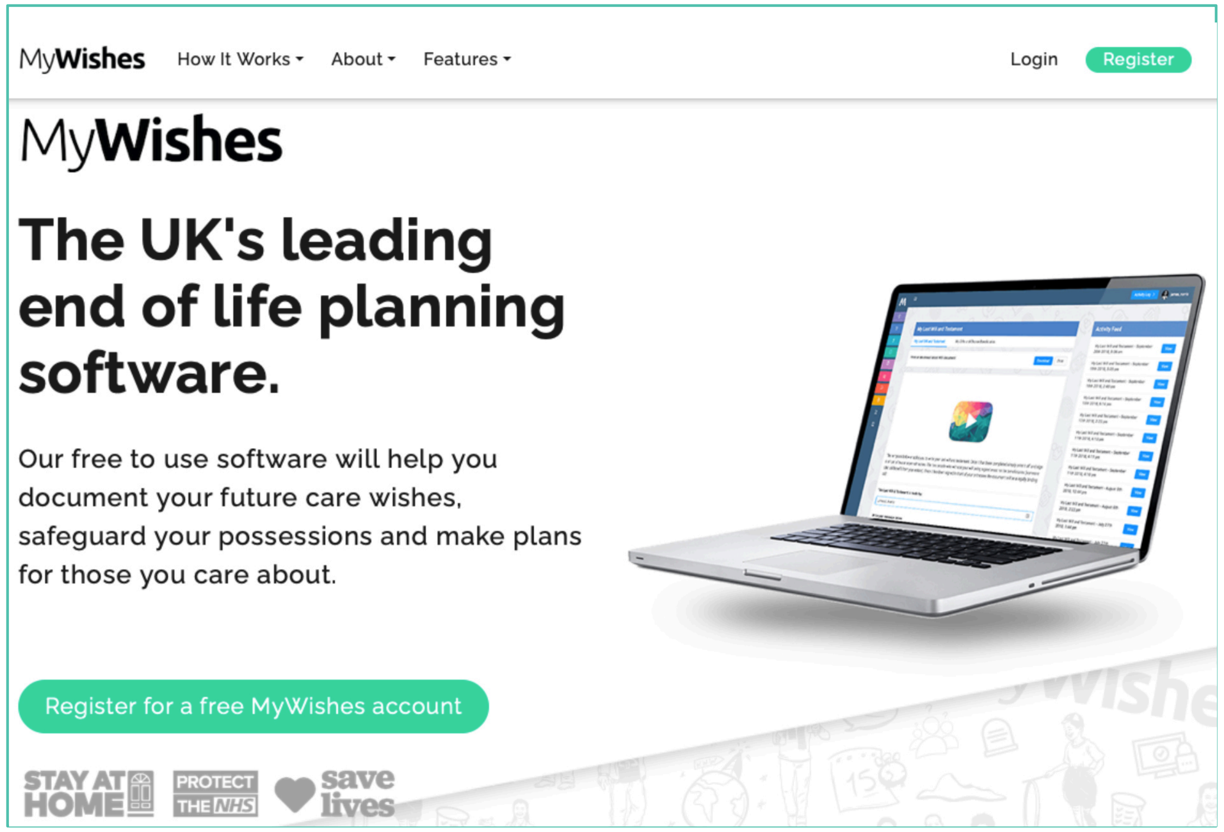
The Project Manager contacted James Norris, founder of The Digital Legacy Association (DLA) and My Wishes, to consider existing resources, tools and training opportunities to create local digital EOL champions.

On the back of consideration of the DLA tools, worked with the Suffolk Good Neighbour Scheme Development Officer to plan approaches to identify people with appropriate interests and skills within existing GNS schemes to "train" and then volunteer as local digital EOL champions, or rather specialists within their existing GNS.

The Steering Group supported this approach. However, it was agreed it was difficult to ask existing Good Neighbours who already had high demands on their time because of the pandemic (creating socially isolated neighbours and more Zoom meetings) to commit to further Zoom training, especially when the preferred training approach was face-to-face small workshops. Consequently, this activity was not progressed during the pilot lifetime but it remains an approach that could be followed in the future.

In addition to this, the work with James Norris led to a joint proposal to the Ipswich and East Suffolk CCG and the End of Life Programme Board in July 2020.

The Proposal built up the existing MyWishes software and online resources that provides a suite of tools and documents to support conversations and preparedness for End of Life. It adapted it to add to MyWishes Near Me, providing a hyperlocal service with information oriented around a well-defined community, which would support the development of Compassionate Communities across the broader IESCCG footprint.



MyWishes

The UK's leading end of life planning software.

Our free to use software will help you document your future care wishes, safeguard your possessions and make plans for those you care about.

MyWishes Near Me provides a more personalised and relevant experiences to people and communities. It also provides a practical digital way of sharing information with key people (including NOK, family, solicitors, and health & care practitioners) including a standard Advanced Care Plan. Certain elements that require interoperability were not in scope for the first stage of the PoC and the EOL Programme Board supported the proposal in principle. At the time, funding was not available.

In December 2020, there were further exploratory discussions as to how these ideas might fit with the broader Digital Programme of the Suffolk and North East Essex Intergrated Care System. This is ongoing.

Work Stream 3

Reducing the stigma attached to EOL

Undertaking public engagement activity to encourage conversations about death and dying

Social Media

The project explored and attempted to use social media especially Facebook to stimulate thinking around death and dying, encourage conversations and signpost to resources.

It set up its own Compassionate Communities Facebook presence but first posts generated some negative feedback directed at the GP Practice, rather than the project itself. It was decided to utilise other networks and partners instead.

A series of facebook posts were sent out independent of the Compassionate Communities Project, but connecting people to the project website and 5 day challenge too.

Funeral music choices formed a popular discussion post.

The Grief post signposted people to CRUSE and generated the sharing of other personal stories.

- *"I got this tattoo at a particular time in my life when I was away from family and alone. The first four elephants represent my Mum, Dad, brother and I; the latter are grandparents, no longer with us but always part of my family and in my heart."*

Compassionate Communities Film

https://compassionate-communities.co.uk

Recognising the vital role Compassionate Companions have in supporting the non-medical needs of an individual in their last months of life and the need to call to arms and inspire others in our communities, a film was made in December 2020. It Involved the Compassionate Companions, individuals they were supporting and other local community members talking about end of life.

The purpose of this film is to:

- Inspire members of the community to become compassionate companions
- Give confidence to people to have difficult conversations regarding end of life choices
- Enable people within communities to recognise their abilities in supporting each other, particularly with non-medical support at end of life
- Raise awareness so that people are better placed to identify when someone may be closer to end of life
- Describe key decisions and processes relating to EOL in a gentle conversation

Key Issues & Recommendations

5a) The Different Models of Community Volunteering at End of Life

Funders had invested in the Compassionate Communities Pilot Project in order to test out a volunteer model of support to individuals approaching end of life, as well as their families and carers.

The scope of the project was also to understand the different models, the roles, levels of training, and volunteer time commitment, in order to inform future decisions to invest more widely and extend the approach into broader parts of Suffolk.
This section summarises that learning and sets out models of support in Suffolk and in the Compassionate City of Plymouth, pioneered by St Luke's Hospice.

This helps to inform future modelling but is also important in relation to providing existing Compassionate Companions options moving forward for continuing to volunteer and support people approaching end of life.

The following section sets out the various roles locally and then compares them to the developments in Plymouth by St Luke's Hospice, which was officially recognised as the first Compassionate city for those at end of life in England, part way through the Suffolk Pilot, in October 2019.

This project did consider, in its original scoping in 2018, the Frome Model which was introduced in 2013 and its impact on reduced hospital admissions was being published and promoted at the same time of this project's exploratory work. It also considered a number of other community volunteer models operating in London. It has not included any comparison of these models in this report because none of them focused on EOL support. All the above models were very much in line with a number of Social Prescribing models that were already in existence in parts of Suffolk in 2018, or other joint Health and Social Care projects that had been tested over two years previously in Suffolk, in particular Local Area Coordination.

This pilot was explicitly looking to develop approaches to improving end of life care, to introduce and test a new approach.

- **The Role of the Compassionate Companion**

What is a Compassionate Community?

A compassionate community includes families, neighbours, local organisations, spiritual support and other health and social care professionals such as doctors, nurses and integrated neighbourhood teams.

People within a compassionate community work together to support an individual, their family and carers to identify and respond to their needs, wishes and choices at the end of life.

Our Compassionate Community will support people experiencing life shortening illness to live as full a life as possible until they die.

It will also enable people to discuss and make informed decisions about their own end of life, whenever that might happen and however far away that might be.

A Compassionate Companion can:

Offer practical support:

Help with small tasks, attend social events or appointments with you, perhaps read aloud, share music, walk the dog etc.

Be there to listen:

Support you, and the people that matter to you, to feel safe and at peace, giving guidance and support in any way it is needed.

Offer connections to the wider community:

Share knowledge of local community groups and resources in your area that might help you live your life as fully as possible, for as long as possible.

Help you to prepare:

Support you to think about your wishes and preferences, how you want to live until you die, where you want to be cared for and by whom. Be alongside you, if you choose, to discuss with loved ones and colleagues advance statements (such as living wills, Power of Attorney) and other decisions important to you.

Offer support to you and those around you during the dying phase:

Recognise signs associated with the end of life, and, with the support of professionals, bring comfort physically, emotionally and spiritually.

Give information and support to loved ones after death:

Give time that is unhurried and respectful, enabling those affected to be involved in the way they wish and informed about the next steps.

DBS
All volunteers had an enhanced DBS check.

Training
The training element of the Pilot was significantly deeper, more costly and required more time commitment than any other model reviewed.

The Foundation course consisted of 32 guided learning hours taught over five days, with an anticipated further 25 hours of independent learning.

It covered models of grief - including anticipatory grief, but this was not the focus on the training. Volunteers have requested further training in grief and bereavement because, in their experience as volunteers, there are intrinsic links and they wish to feel better equipped to deal with the issue.

In addition a two hour safeguarding training session was delivered by Community Action Suffolk, for which volunteers all received a certificate.

There are currently five active volunteers, two of which have completed the full Diploma training. The full Diploma training included an additional 15 days of face-to-face training, extensive personal learning hours and assignments (as set out in Chapter Two).

Referrals and Matching
Referrals come from within the GP practice; the GP matches according to volunteer availability, geography and personal experiences.

Supervision and Support
Emphasis was placed upon ensuring appropriate monthly group supervision with a psychotherapist, access to a project manager, and other available 1-2-1 mentoring and peer support through membership with End of Life Doula UK.

The importance of this is discussed later.

WITHIN EAST SUFFOLK

The Role of St Elizabeth Hospice Home Sitters

St Elizabeth Hospice have a volunteer service called Home Sitters. Volunteer sitters “visit a patient’s home for an hour or two to keep them company and talk to them, offer a listening ear and to give their carer a break to pop out, run errands, or have some ‘me’ time.

DBS
All volunteers have a DBS check.

Training
The Hospice provides its own online training in the following:

- Data Protection
- Health and safety
- Food hygiene (they are able to make a drink but not to provide personal care)
- Emotional wellbeing (how to take care of themselves as well as giving support to the patient.)

Referrals and Matching
Referrals come through the Community Team; over the last few years the service has grown and there are now 12 volunteers.

Supervision and Support
All sitters attend a Welcome Day and shadow another member of the team. The Hospice holds a meeting with them all every three months.

More information can be found here:

www.stelizabethhospice.org.uk/stories/volunteer-home-sitters

The Role of St Elizabeth Hospice Bereavement Volunteers

St Elizabeth Hospice also has another formal volunteer service established in 2020, offering bereavement support. They provide telephone support to people at home, responding to the individual’s emotional needs resulting from a bereavement by providing time and a listening space. There are currently six volunteers.

DBS
All volunteers have a DBS check.

Training
The Hospice provides its own three hour training in the following:

- Working with bereavement and
- Listening skills

Referrals and Matching
Referrals come through Emotional Well-Being Team and are triaged for suitability.

Supervision and Support
Volunteers have access to the Coordinator and the Hospice provides monthly group supervision.

The Suffolk Good Neighbour Scheme

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A Good Neighbour Scheme is a voluntary initiative run by a group of local residents, who want to help their people in their locality to enjoy a better quality of life by offering them support with every-day tasks. This helps to build a stronger and more resilient community where people know each other, providing help where needed. Generally the schemes operate via a mobile phone, which is held by a volunteer who consequently puts users in touch with a volunteer who can help them.

All Schemes across Suffolk are run by volunteers, committees and coordinators at a local level and self-manage. As such, each Scheme's activities and support offers vary, but might include things like:

- Providing transport to the GP, hospital or shops, or even work (for instance, if somebody is injured and can't drive themselves).
- Getting in some groceries because for somebody who is unwell, or has a poorly child and can't get out of the house.
- Help with filling in a form, or using technology.
- Help around the home or garden.
- Company or friendship.
- Advice on what is available locally, such as groups, activities, or local tradespeople.
- Hosting social opportunities such as Coffee Mornings or Afternoon Teas, or arranging trips and outings.

DBS

Only GNS volunteers carrying out regulated activities or handling/processing personal data (phone holders/committee members for example) are required to have an enhanced adult DBS check carried out.

Training

The Network provides a resource pack and toolkit, including a Volunteer Information Pack providing a paper induction into the group. It includes a review of the group's policies, procedures, and good practice, and an overview of the voluntary role and expectation, as well as helpful information and resources such as safeguarding information, and signposting for other organisations that may be helpful to community members or the volunteer.

At a local level, most groups will provide a light induction to provide an overview of activities, processes and expectations for new volunteers. When some new schemes form, it is initiated as a group gathering so volunteers could get to know each other, at the same time as receiving information and sharing good practice. At this time, a Safe & Sound session (introduction to safeguarding and keeping yourself safe as a volunteer) can be offered. Some groups offer shadowing, or buddying where this is appropriate and possible, to help induct a new volunteer.

Supervision and Support

As it is part of the wider Good Neighbour Scheme Network, each scheme can access support and guidance from the Suffolk Good Neighbour Network Development Officer. The Officer brings coordinators together through an annual meeting, direct contact and regular bulletins that enable them to:

- Discuss relevant current issues
- Share good practice
- Offer peer support

More information can be found here:

www.suffolkgoodneighbours.co.uk

ELSEWHERE IN ENGLAND

St Luke's Hospice Plymouth/Plymouth - A Compassionate City

"A Compassionate Community gives 'ordinary' people the skills to be able to address issues raised by end of life, life limiting illnesses and other losses, and to be a helpful, empathic ear."

The St Luke's Hospice (SLH) model incorporates community involvement at various levels but no-one is regarded as a formal volunteer of the Hospice. Information sessions focus upon four key components to being compassionate:

THE LEND MODEL

- Listen - to help people to talk over what they need, their worries or what they want to do.
- Empathise - to acknowledge their situation and respect their choices.
- Notice - when some-one may need some company, to have a chat or a helping hand… or when they don't!
- Do - by giving practical support, signpost to services and resources, work with others to be a compassionate community.

DBS

DBS Checks are not required and as such Compassionate Friends, including the Co-ordinator, who are not known to the person needing help, must not engage in "regulated" activity.
To safeguard the person needing help and the Compassionate Friends Network, Health and Social Care Professionals use a safeguarding and DBS risk assessment for Compassionate Friends to determine if Compassionate Friends will be appropriate. The person needing support is asked to give their consent for the involvement of Compassionate Friends once they have been informed that they do not undergo any of the usual volunteer checks.

It is also very likely that the Compassionate Friend will probably already be known to the person and/or family or their friends as the network will have been formed from their existing support and community groups. Therefore, they or their family will have already established that they are reliable and trustworthy.

There is a confidentiality and task agreement, which outlines the activities Compassionate Friends can engage in and the activities they shouldn't engage in.

Training

There is a free two hour Compassionate Friends Information Session for local people, the purpose of which is to:

- To raise awareness of End of Life Care Compassionate Communities, Organisations, Friends & Networks

- To break down taboos and myths about death and dying
- To reflect upon how to respond compassionately and engage in End of Life Care conversations
- To signpost to key services and resources
- To develop Compassionate End of Life Care Friends
- To encourage the development of local Compassionate Communities

At the end of the session participants are encourage to make a pledge to LEND a helping hand, a friendly ear, or by practical support to someone in the community.

A pledge might also include:

- Be part of a Advanced Care Planning Workshop
- Be part of a Compassionate Café
- Being a Compassionate Friend in a Network
- Become a Compassionate Friend Co-ordinator
- Become a Compassionate Friend Champion
- Attend a Compassionate Friend Forum

There is voluntary progression to a free 3.5 hour Compassionate Coordinators Training Session

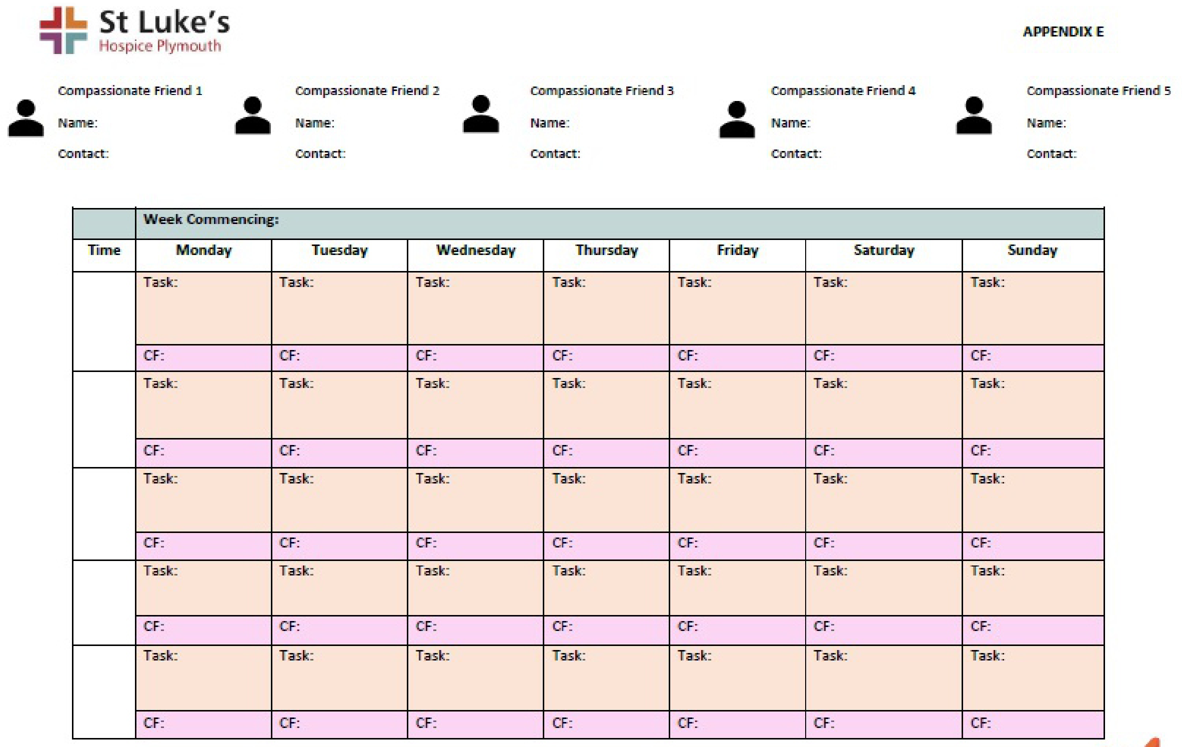
Coordinators ensure that each network of friends has someone who will coordinate and look after them as they respond to requests for help.

This session includes:

- Training on Safeguarding
- Building trustworthy community networks through Supportive Mapping
- Confidentiality & setting boundaries
- Rotas & managing capacity to engage in network whilst ensuring friends do not over commit
- Effective and confidential communication process
- Managing friends data (GDPR)
- Personal Safety

- Supporting person with “non-regulated” tasks
- Building security
- Self-care, supervision, support systems, network events
- Signed confidentiality agreement

A Coordinator works with its network of friends to create a rota of support:



St Luke's Hospice Plymouth

APPENDIX E

Compassionate Friend 1
Name:
Contact:

Compassionate Friend 2
Name:
Contact:

Compassionate Friend 3
Name:
Contact:

Compassionate Friend 4
Name:
Contact:

Compassionate Friend 5
Name:
Contact:

	Week Commencing:						
Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
	Task:	Task:	Task:	Task:	Task:	Task:	Task:
	CF:	CF:	CF:	CF:	CF:	CF:	CF:
	Task:	Task:	Task:	Task:	Task:	Task:	Task:
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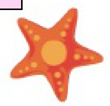
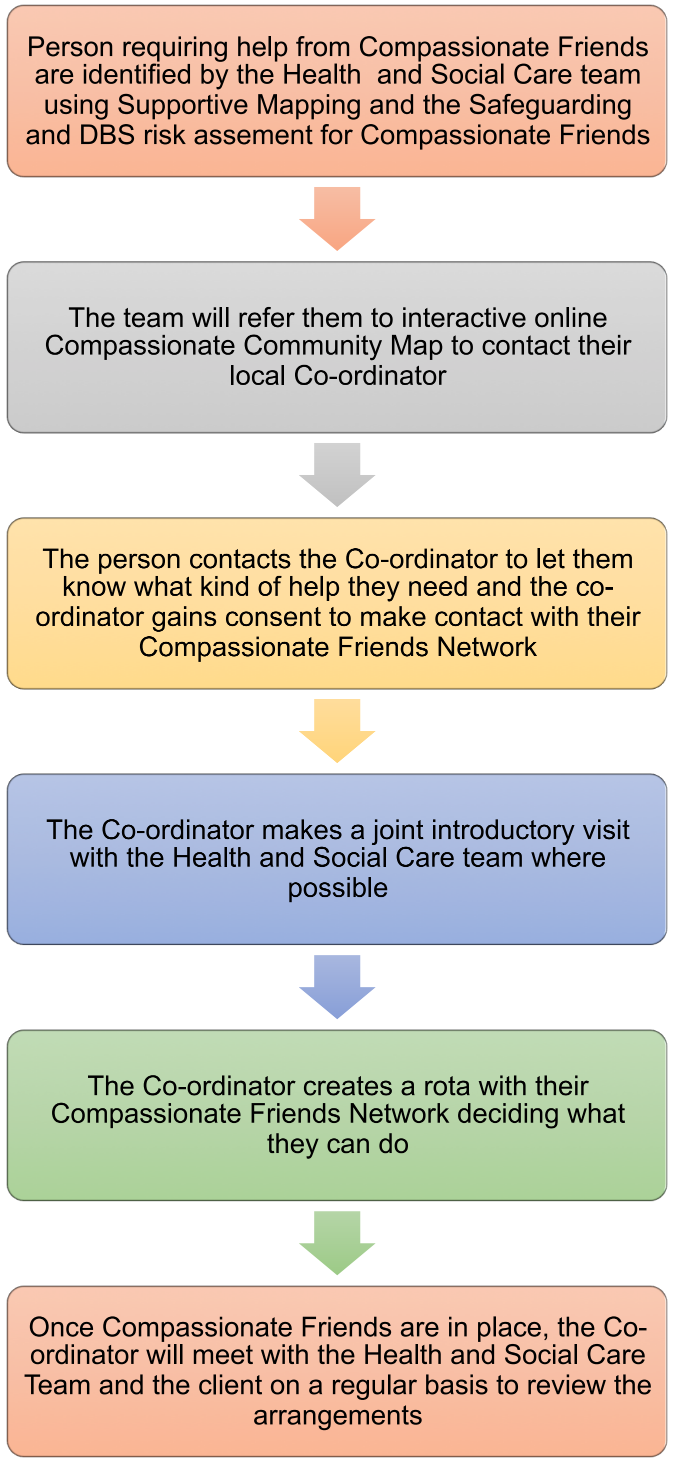


Referrals and Matching

The model has the following referral process:



Person requiring help from Compassionate Friends are identified by the Health and Social Care team using Supportive Mapping and the Safeguarding and DBS risk assement for Compassionate Friends

The team will refer them to interactive online Compassionate Community Map to contact their local Co-ordinator

The person contacts the Co-ordinator to let them know what kind of help they need and the co-ordinator gains consent to make contact with their Compassionate Friends Network

The Co-ordinator makes a joint introductory visit with the Health and Social Care team where possible

The Co-ordinator creates a rota with their Compassionate Friends Network deciding what they can do

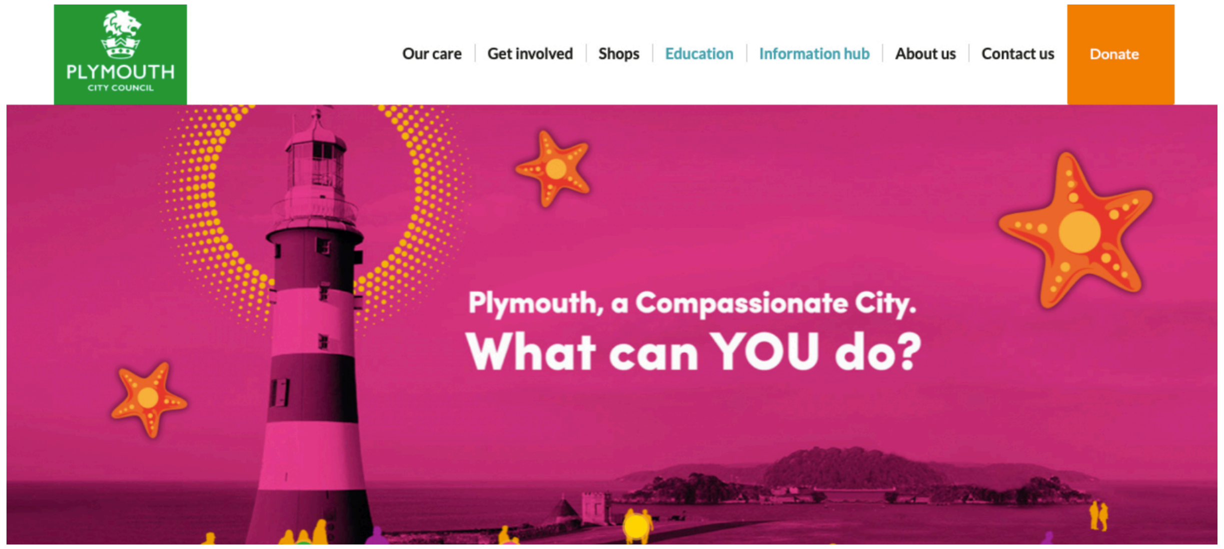
Once Compassionate Friends are in place, the Co-ordinator will meet with the Health and Social Care Team and the client on a regular basis to review the arrangements

Supervision and Support

The SLH Community Development Team provides co-ordinators training, guidance, and links to the local and SLH and end of life care services. SLH will host a regular forum for co-ordinators to share ideas and learning. A Coordinator can contact the SLH Community Development Team if there are queries or concerns.

More information can be found here:

www.stlukes-hospice.org.uk/plymouth-a-compassionate-city



5b) The Importance of the Compassionate Companion Role

As part of the project a film was made to describe and promote the role of the Compassionate Companions and can be found at:

https://compassionate-communities.co.uk

This Pilot Project Demonstrated:

whether face–to- face or remotely, Compassionate Companions have provided:

- Befriending and companionship that has alleviated feelings of loneliness and isolation.
- Emotional support
- Advocacy support,
- Practical help,
- Alerts to the medical team of acute medical care needs
- Help to facilitate otherwise difficult conversations with family and loved ones
- Advance planning, updating of existing will, resuscitation conversations.

Additionally, we have observed that:

- People approaching end of life are not always aware of the choices available to them
- People approaching end of life often find it difficult to have conversations with those people that matter most to them
- As companions develop befriending relationships, these conversations often naturally emerge, and a Compassionate Companion can also help to facilitate these conversations with family and carers.
- When an individual is able to accept the prognosis of their illness, a desire to "put things in place" such as a will, enabled conversations to occur comfortably and with confidence.
- A patient in their last months and weeks of life require proportionately more non-medical support than medical; a combination of these types of support can enrich and empower them and their families to make informed choices and plan for a good death.
- Further work is required to develop the companion role alongside professionals to achieve the aspiration for a seamless 'one team' palliative care holistic service.

Furthermore, from our subjective experience so far, supported with anecdotal evidence from national initiatives we hypothesise that:

- Compassionate Companions play a vital part in supporting non-medical needs of an individual at end of life. They can make the difference between an individual having a prepared and planned end of life at home and a reactive crisis response ending in an unwanted hospital death.
- By developing relationships and relaxing the boundaries between medical teams and volunteer compassionate companions, essential proactive care wishes can be shared and documented in medical records for all carers and professionals involved so to have the best chance of honouring them for the individual.
- By having more time to spend with an individual, a companion can initiate what might be difficult but essential conversations around preferred place of care and death; discussions around active treatment versus comfort palliation, resuscitation etc. Working and communicating these discussions with professionals can enable a healthy and planned conversation with the GP/ medical teams to finalise and complete documentation as appropriate.
- Companions can recognise deterioration and confidently communicate to appropriate medical teams to ensure appropriate medical care is provided proactively. This would help reduce the common crises and distress otherwise seen so often in EoL care.

5c) The Importance of Management and Supervision

The Pilot Project has demonstrated:

- Compassionate Companions need a volunteer coordinator and regular clinical supervision, access to each should remain separate and defined.
- The Diary and Log that Compassionate Companions were asked to complete after each interaction provided a vital tool to support management and supervision.

Compassionate companions need a coordinator/ line manager for logistical and practical purposes (recruitment, governance, practical troubleshooting).

The role of Project Manager and Volunteer Coordinator is distinct. Whilst the 0.4FTE Project Manager was able and skilled to adapt to Volunteer Coordinator, this would not have been possible in normal circumstances. COVID prevented delivery of a good deal of the Project Plan and possible matching of Compassionate Companions. However, it did facilitate the Project Manager taking on the role of Volunteer Coordinator.

There has been mixed feedback from the Compassionate Companions and Project Manager in relation to Compassionate Companions group supervision. This is reflected in part in the report that Stephanie Walker, Psychotherapist engaged for the duration of the pilot has provided below and includes recommendations in relation to clinical supervision moving forward.

Report written by Specialist Group Psychotherapist Mrs Stephanie Walker:

Objective of Clinical Supervision

Supervision is a joint endeavour in which the practitioner (the Compassionate Companion), with the help of the supervisor (myself), attends to their clients. My role as supervisor was to integrate the developmental role of educator with that of providing support to the companion, and to ensure the quality of the compassionate companion's work with their patient.
In the process of discussing a compassionate companion's case load, they have an opportunity to share knowledge and experience, seek support and to challenge subconscious and unconscious practices, exploration of which underpins safe ethical practise.

Focus of the Sessions

The group, consisting of seven compassionate companions, plus the project manager and myself, initially met face to face for six sessions. These first meetings were about getting to know each other, setting up guidelines on confidentiality, and establishing how the needs of individual compassionate companions could be met in supervision and by the group process. Such early interactions are vital to the subsequent cohesion of a group.

As supervisor I recognised that, given this was a pilot project, time was needed to address some of the practicalities of the compassionate companion's role. In these initial meetings, attention was paid to the high levels of anxiety that some group companions were feeling in relation to administrative tasks.

An example of this was how to understand and introduce to the companion the 'yellow folder' and other such administrative yet sensitive information.

All group compassionate companions displayed an enormous amount of enthusiasm and interest in the project. Some of them held strong views about how they wanted to incorporate their own style of working. Time was often needed to try to agree appropriate responses to some of the issues raised, as compassionate companions learned more about the restrictions on incorporating personal perspectives into their role.

An example we addressed was the idea that it is not safe for compassionate companions to be working with vulnerable patients when they themselves are affected by the situations they encounter (both consciously and subconsciously) and put their designated patient at risk in some way. The role of the external supervisor is therefore to provide a non-involved perspective and gently challenge a compassionate companion's understanding or view of a situation.
The group was beginning to show signs of developing into a more reflective process, with compassionate companions becoming more open about their feelings and experiences, when the pandemic struck. The disruption caused by this resulted in the focus of the sessions moving away from the compassionate companion's personal process in view of their patient, to a need for the group to adapt and manage the restrictions that Covid now brought to bear on their role and the continuation of the project.

To continue the delivery of supervision and support, it was agreed that our sessions would move from face-to-face to Zoom, a new technology for most of the compassionate companions. We initially started with two-hour meetings, but this was soon reduced to one hour due to feedback from the companions than it was too long to be online. This reduced the time that everyone had to talk about their own caseload and thus diminished the opportunity for deeper discussion and reflection. Following these changes, compassionate companions did acknowledge the value of knowing that there was a monthly space and support available to them, and everyone was happy to continue with our Zoom sessions.
Emphasis in the supervision shifted to compassionate companions fears around how to keep the project running and support the patients in the project through this transition, now that face-to-face work between the compassionate companions and their patients was prohibited due to lockdown restrictions.

Time was needed for the compassionate companions to air their own views on the practicalities of working safely and their personal anxieties about the virus. The compassionate companions used supervision as a platform to air frustrations with the project and the restrictions that the lockdown had placed on their developing relationship with their patient.

It was immediately clear to me that conducting group supervision during a pandemic and online was going to be difficult, particularly given the pilot status of the group and its consequent lack of experience to fall back on.

Supervision normally requires the time and space to hear what a person is both saying and not saying. In a Zoom environment, people often tend to deliver factual input and then mute their microphone, which makes it difficult to get a sense of things that may have remained unspoken. They also interrupt one another, which stops the flow of exploration of an issue.

During the time that we were working on Zoom, compassionate companions nonetheless had the reassurance of knowing that they could reach out for support without any judgement, and were developing peer support locally. Supervision time did provide a platform for issues and frustrations to surface around compassionate companions feeling of inadequacy and the need for training in how to approach delicate end-of-life conversations and bereavement issues.
Time was also needed for compassionate companions to discuss their responses and feelings about other founding compassionate companions who had chosen to leave due to their frustrations at not being matched with a patient and were seeking an opportunity to use their helping skills in another format.

Challenges in Supervision

In hindsight, it would have been better to wait before starting the supervision until after completion of the setting up process, when the compassionate companions were still trying to establish parameters for their role. At this early stage, the compassionate companions were anxious about following procedure correctly and having clarity about their role, thus setting a precedent for supervision time instead to be given over to, and confused with, discussion of the immediate practicalities of their role.

The presence of the project manager in the sessions and the consequent mixing of objectives of the sessions contributed to a perception among the compassionate companions that supervision was about problem solving, whereas it is in fact aimed at getting compassionate companions to focus on their own process and discover the answers for themselves.

Sometimes issues that would have been useful for discussion in supervision had been discussed with the project manager prior to the session and therefore the compassionate companions no longer felt it necessary to discuss an issue which in their eyes had already been resolved, but which might nonetheless otherwise have provided useful information about the individual's own process to supervision.
The matching of compassionate companions to patients was slow to start and roughly half were matched during the pilot.

The group therefore lacked coherence, with compassionate companions without a patient wishing to discuss their frustrations at that situation. This made it difficult to find common themes to address during supervision.

Looking back, the fact that none of us had any sense of how long the pandemic might continue meant that there was no systematic resetting of goals and parameters. Instead, we simply continued from month to month.

The frequent fluctuations in Covid restrictions meant that in supervision the compassionate companions often needed to check practical issues and to oscillate to the project manager for decisions on how best to work within the parameters of the pilot.

Recommendations for Supervision Moving Forward

- *It is crucial that compassionate companions are selected on the basis that they are psychologically minded and therefore able to engage and willing to share in the supervision process. One of the challenges as a supervisor was to help some compassionate companions overcome the notion that simply wanting to help in a good-hearted way is sufficient for them to be successful in the role.*
- *Supervision is crucial for the compassionate companion's role. Without this platform in place there is a risk of collusion, as well as a potential lack awareness of how their own personal process and circumstances may encroach on their client work and of how the client work may be affecting them in turn. The objective is therefore to create a space where time is given to supporting personal and professional growth resulting in ethical quality practice. Compassionate companions cannot work alone, and need someone to whom they are accountable and who can guide them when necessary.*
- *Supervision should commence when the group process is needed, and not by default at the outset of the project. It may be helpful for the project manager to be involved at the offset, but only for observational purposes and not for involvement in practicalities and administrative issues.*
- *Membership of the group needs to be considered carefully. If the team is made up of people with different professional roles, such as by involving the project manager, there is a risk that the boundaries between the role of the supervisor and the project manager will be blurred for the compassionate companions, leading to confusion about the purpose of, and need for, the supervision group.*

- The supervisor should have a formal opportunity to meet the project manager for discussion of any relevant issues on a regular basis, separately from the supervision meetings.
- Sessions should ideally be held monthly for two hours, restricting compassionate companions' numbers to eight, to allow time for each compassionate companion to participate and feedback their reflections to the group.
- Prospective compassionate companions should meet initially 1-2-1 with the supervisor to give the supervisor an opportunity to assess whether they are psychologically minded and whether there are any blocks to them engaging with the supervision process.

- *The capacity and willingness of the compassionate companions to be open and transparent is essential to the development of the compassionate companion and the safety of the patient.*
- *A contract needs to be agreed between supervisor and each compassionate companion about what to expect of supervision and the boundaries of their work.*
- *I would recommend that it is only when compassionate companions are assigned to a patient that they join in the supervision group, thus reducing possible disruption of the flow in content as set out above.*
- *Compassionate companions should be encouraged to prepare for supervision such as by asking themselves: Why am I going to this session? What do I need to talk about? What reflections on client work and any external factors that may be impacting I do I have to discuss?*

5d) The Importance of Compassionate Companion Support and Training

This Pilot Project Demonstrated:

- Peer support is important and can be effectively provided through a range of support mechanisms. (Three of the compassionate companions who are still supporting individuals value the monthly peer support provided through their membership to EOL Doula UK). All Compassionate Companions have offered peer support to each other throughout the project too.

- Where individuals were reluctant to discuss end of life choices, some compassionate companions lost some confidence in their perceived ability to engage in such conversations. Recognition of these dynamics through group supervision, project management and peer support reassured these Compassionate Companions, and recognised a need to support perceptions of companions that if an individual is not ready to discuss EoL matters it is not a failure of their role.
- The multiple forms comprising what is collectively called the 'Yellow Folder' - resuscitation, My care wishes, advanced planning forms etc - in East Suffolk, and the training around it, continues to require support for Compassionate companions.
- Confidence comes with practice and experience. Unfortunately, not all Compassionate Companions had identified patients to support and therefore could not utilise their skills and knowledge as soon as intended.
- Compassionate Companions requested further training and support in understanding grief and supporting the bereaved.

5e) Recommendations

- With further funding there are opportunities to recruit, train and support more compassionate companions, and, in doing so, to develop compassionate communities to include businesses, towns and cities.
- A review of research papers shows there is no national standard or proxy for evaluating the efficacy of compassionate companion - like roles (including other titles such as hospice neighbours/friends; doula's; hospice sitters and bereavement support etc). With further funding there are proposals ready to address this and therefore to pioneer testing the hypothesis that compassionate companions can make the difference between a good and a bad death.

- Compassionate Communities can be considered as part of the foundation tier of the inverted pyramid of care delivery. Integrating with our voluntary sector colleagues including Good Neighbourhood Schemes and Social Prescribing, the compassionate companions model has potential to fulfil the ambitions of Suffolk's Public Health Report : Lasting Legacies and the Forward Plan (see below)
- Training, for example in Advance Decision planning, and conversations around resuscitation, after initial classroom support, can be further enhanced through direct experience which could be supported by companions accompanying hospice clinical nurse specialists, primary care clinicians and/or community teams within Integrated Care Networks during visits to their matched patents.
- Continued encouragement to widen the referral process and encourage all community teams to identify individuals who might benefit from compassionate companion support can be planned. This would include hospice clinical nurse specialists, professionals within the Integrated Network Teams, Social Prescribers, as well as within neighbourhoods and communities themselves such as via Good Neighbourhood schemes.
- The identification of individuals who might benefit from a compassionate companion needs to consider not just the life limiting illness or social situation of the individual, but the understanding by the individual of the full range of support, skills and knowledge that a Compassionate Companion can offer.
- One size does not fit all. We all have different personalities. This is personalised patient centred care and matching patients with companions needs to be done with informed and sensitive coordination. One suggestion is for the clinical nurse specialist or designated PCN clinicians to initiate conversations with potential patients and to then liaise with the coordinator regarding the most appropriate match.

Transitioning from Pilot Project to further development of Compassionate Companion Role:

- The current compassionate companions, despite the pilot project officially ending March 31st 2021, are keen to continue in their roles. They will have weekly zoom meetings with Dr Crockett and ongoing supervision until further options are explored.
- They have all expressed a desire to support the development of the project in principle, and to be involved in its evolution. Advance Planning training is currently being offered and plans are being explored to provide Advance Planning and bereavement care training in the near future.

- Early discussions are being held with St Elizabeth Hospice as part of their volunteer Programme and also with End of Life Doula UK for both role development as well as training opportunities.
- Early discussions are being held with other areas to scope the potential development of this project including the Integrated Care Academy.
- Any model of a companion role must be sustainable and will require investment to train and support, and to integrate as part of a seamless team including clinicians and community workers to support people at end of life.

And Finally, Chances to Reclaim a New Beginning

Professor Kellehear's pioneering work as described in Chapter 1, together with the information gathered by this Pilot Project at grass roots level with stakeholders throughout the system, recognises the inadequacies and inequalities of palliative care provision in the UK.

Our model as a compassionate communities project was piloted in East coast Suffolk between March 2019 – March 2021.

Integrated Care Systems (ICS) and Alliances are partnerships between organisations that meet health and care needs across an area, to coordinate services and plan in a way that enables strong communities, supports wellness, improves population health and reduces inequalities between different groups.
The NHS Long term Plan states that personalised care will become business as usual across the health and care system.

https://www.longtermplan.nhs.uk/

Ipswich and East Suffolk Alliance set out a clear vision, mission, set of values and objectives and aligned activities for the next 5 years.

https://ipswichandeastsuffolkccg.nhs.uk/Portals/1/Content/Alliance/2854%20NHS(IESCCG)-Alliance%20Strategy%202018-23_FINAL.pdf

The mission is ‘To work seamlessly together with you’

The collective aim is to make a difference to the issues that matter to people. End of Life care is embedded in these ambitions for transformative care.
It has for many years been the aim of our Integrated Health and Care system to move to a more proactive, collaborate ‘Out of Hospital’ model which aligns with honouring the choices for the overwhelming majority of those at End of Life in a prepared and seamlessly supported way.

Ten key themes were identified through Alliance level collective learning with system partners, recognising also that Covid-19 further amplified the many existing inequalities in our communities;

- We underestimated the inherent resilience in our local communities
- Enabling collaboration is even more important now than it ever was
- We are more adaptable than we thought – with a collective focus we can move mountains
- The safety, flexibility and resilience of our people and workplaces are vital
- We need to plan both for the many and the few
- Adopting new technology has potentially brought new opportunities and challenges
- Knowledge is key - we need the right data and intelligence to deliver better care together
- We need to be joined up across sectors about funding and investment
- In recovering our services we need to ‘build back better’ and be prepared to face future challenges

It is powerful to realise that these were all themes known and shared by the community themselves (albeit in different language) in Hollesley village Hall in November 2018, They were already known by the people we are employed to serve - the people we live with, in our personal communities, as friends, neighbours, and some existing volunteers.

Using the lessons learned and recommendations from this project, there is an opportunity to develop fully supported and evidenced based community volunteer End of Life care provision. There is a need to enhance positive palliative care, there is a need to attain the ambitions, visions and aspirations for End of life care for both patients and families as well as providers and commissioners.

Suffolk could lead as pioneers in establishing a national standard to evaluate the efficacy of non-medical support in EoL care using our compassionate companion model.

This could be the first step towards a truly joined up approach – reclaiming the process of dying and death as a natural process, not a medical procedure.

Managing End of Life care in the community, by the community.

This project built upon the existing compassion within local people, living and working in a small geography in East Suffolk.

Together they have found ways to support individuals to live their lives as fully as possible and to consider their choices until they die.

Compassionate Companions have provided non-medical support to people with terminal diagnosis, their families and carers.
In addition, they have committed time and energy to share information and encourage people at any stage of life to have conversations, make informed choices and reduce the stigma attached to end of life.

We thank every one of those Compassionate Companions from the bottom of our heart.

Dr Lindsey Crockett & Rachael Metson