



# 1. Context

During the worst of the COVID pandemic Healthwatch Brighton and Hove published [“A Good Send-Off?” Patients’ and Family’s experiences of End of Life Care’](#), a hard hitting report about the pre-COVID experiences of 15 people whose end of life care had been difficult and unsatisfactory.

The main finding of this report a year ago was that if people facing end of life care are supported by a specialist team providing personalised care their ending was dignified. Healthwatch Brighton and Hove found that if this was not the case, their hospital discharge and subsequent care at home was an 'event' and not a dignified process. Brighton & Hove City Council and the NHS accepted the report, all its recommendations and promised to fix the problems.

A year on Healthwatch Brighton and Hove wanted to hold them to account and hear from local people about their experiences too. Healthwatch in Sussex, a partnership between Healthwatch Brighton and Hove and Local Healthwatch in East and West Sussex, held a webinar on Wednesday, 12th May 12.00 - 2.00 pm. Local people and professionals across the county were invited to have a conversation about this topic and to share their experiences of planning for End of Life or helping others to do so.

Publicity was sent out via the three local Healthwatch using mailing lists and social media. The media were also engaged via Healthwatch Brighton and Hove.

A total of 110 people registered and 74% (81 people) attended the webinar itself. Approximately one third (26%) were not in attendance due to personal reasons or technical difficulties with using the online platform and were instead offered access to the recording of the webinar. The registrants represented Members of the public, patients and family and friends of patients (totalling 25%) and health and social care professionals (75%).

The event was chaired by Fran McCabe, one of the co-writers of [“A Good Send-Off?” Patients’ and Family’s experiences of End of Life Care’](#). Fran McCabe is the Chair of Healthwatch Brighton and Hove and has 50 years in health and social care. Specializing in older people and with personal experience of family members at the end of life, she is passionate about ensuring more attention is paid to making people’s end of life experience and their death as good as it can be.

Three speakers shared their own and professional experience with participants:

- Dr Marian Messih, Roving GP with a special interest in End of Life Care for elderly people - [Integrated Care 24](#)
- Li Mills, [End of Life companion and Funeral Celebrant](#)
- Christine D’Cruz, [Healthwatch Director](#) and co-author of “A Good Send-Off”

Participants were invited into breakout sessions, which provided an opportunity to share personal experience. Participants also tried to answer the following question:

## **“Thinking ahead to the end of life, what three things would be most important to you?”**

After the breakouts and once everyone had returned to the main room, facilitators fed back to the room each of the three things their group had focused on. Fran McCabe (Chair) completed the feedback with reflections from her own group and a short overall summary.

Sarah Pearce, Head of Integration, West Sussex CCG was invited to provide some reflections on the session so far. This was followed by question and answers, in which Fran McCabe (Chair) invited the earlier panel (Dr Messih, Li Mills & Christine D’Cruz) to join Sarah. Two nurse consultants also offered to be available to take questions on the day. These were Lisa O’Hara, Nurse Consultant Palliative & End of Life Care, Brighton General Hospital and Sue Lyne, Health Nurse Consultant for frailty in East Sussex, East Sussex HC Trust.

Fran McCabe (Chair) concluded that from the discussions today, “We’ve got some benchmarks for what End of Life Care should look like. We’ve talked about ReSPECT and this seems to be the vehicle by which to do this. I hope this will be the start of some change, the start of some improvement, the start of networking, for a better End of Life Care for people in this area.”

### **The following summary presents:**

- Summary of presentations.
- Key Themes.
- Questions and Answers raised in the webinar.
- Taking this work forward.
- Signposting - useful information regarding End of Life Planning.

To watch the recording of the webinar, and to access copies of the reports mentioned above, please visit:

<https://www.healthwatchbrightonandhove.co.uk/news/2021-05-28/conversations-about-end-life-whats-important-you-webinar>

## 2. Summary of presentations

### **Dr Marian Messih, Roving GP with a special interest in End of Life Care for elderly people - Integrated Care 24**

Dr Messih explained how Advance Care Planning was an important “process that supports adults at any age or stage of health in understanding and sharing their personal **values, life goals, and preferences** regarding future medical care”. (Definition by *International Consensus Definition of Advance Care Planning (Sudore et al 2017)*). She also presented the newly revised Recommended Summary Plan for Emergency Care Treatment (ReSPECT) form (Version 3). This is a type of advance care plan relevant for emergency situations that is completed as part of a shared conversation between the patient and their clinician. This version now includes a discussion around choice between “living as long as possible” and “quality of life”. Dr Marian explained that her experience included patients who had decided that quality of life was more important to them, even when this could be at the expense of living longer.

### **Li Mills, End of Life companion and Funeral Celebrant**

Describing her role as part of the network, End of Life Doula UK, Li said it was easier to understand if we think of it as a “companion” at the end of life. Doulas “walk alongside those with terminal illness to provide emotional, spiritual (if needed) and practical support, filling in any gaps between the other professional support the person is already engaged in”. Doulas also support the person’s family and close friends where this is needed. The role varies according to the person’s wishes. It can include talking to them about the illness itself and about plans for when they are gone, but it can also include helping with home chores and childcare where the person is too ill to be able to perform these tasks themselves.

Li also organises death cafes. While not providing grief support or counselling, death cafes are where people meet to have an open discussion about what death looks like (usually in a relaxed environment over a cup of tea). As a funeral celebrant, Li helps arrange funerals, in the case where the deceased person didn’t hold any particular spiritual belief. Li works with the family and prior to death, the person themselves, to arrange a ceremony fitting to the person’s wishes.

### **Christine D’Cruz, Healthwatch Director and co-author of “A Good Send-Off”**

Christine spoke about the report that she co-wrote with Fran McCabe (Chair) and which also led to a [“One Year On” Report](#). Christine highlighted findings from the original report, that demonstrated how people interviewed were in the last few months or weeks of their life. The people interviewed had experienced numerous re-admissions; Not enough support at home; Care of variable quality; GPs were rarely involved; Failed discharges; and lack of early planning including no memory of the ReSPECT form. After the patient died, families were rarely followed-up by medical staff, including their GP. Christine closed by asking that “We need to prioritise transforming service delivery from a patient’s perspective and not confusing it with integrating organizational change”.

**Sarah Pearce, Head of Integration, West Sussex CCG**

Sarah was asked to provide a reflection on the themes discussed from earlier presentations and feedback from the breakout rooms. She said the webinar had “brought home” how important it is to ensure people are at the heart of discussions. Commissioning was often around practicalities, but a holistic approach was more effective, ensuring that people’s choices and preferences were part of the decisions made about services. Welcoming the recommendations from the Healthwatch reports “A Good Send-Off” and “One Year On”, Sarah said these would be the commissioners’ focus for plans coming out of the pandemic, ensuring that a community-based approach included staff training and education.

### 3. Key Themes

It is so important to share with loved ones what you, the patient, really want, because one day they may have to advocate on your behalf and legally a doctor cannot just do what a patient wants, without also considering what is in the patient's best interests."

**Prof Bobbie Farsides, Brighton and Sussex Medical School**

Feedback from the breakout sessions in response to the question "Thinking ahead to the end of life, what three things would be most important to you?"

#### Patients want to govern their own end of life journey

- Patients want to be listened to and at the centre of the decisions over their care and treatment.
- Patients want to be involved in any decisions made about Do Not Resuscitate and to ensure their decision predominates.
- Where the patient is unable to express their opinion, they want to ensure that advance planning has allowed them to be specific and an advocate is able to speak out on their behalf. This is equally true of patients in care homes, as it is for patients in their own home or in hospital.

Patients want "End of Life [to be] a dignified process, not an event."

**Prof Bobbie Farsides, Brighton and Sussex Medical School**

#### Patients want the right to choose

- Patients want to choose where they die, and most will opt for care at home, if possible.
- Most patients will opt to have their loved ones close by, but not all patients wish for their loved ones to be next to them at the point of death. This wish should be respected.
- Patients want to have the *choice* to engage in honest and transparent conversations about what is about to happen to them.
- It is important for patients to have an honest conversation with themselves and consider what they really want before expressing wishes to their loved ones.

Patients and loved ones want "Hope vs Honesty - to hope for the best, while preparing for the worst."

**Michelle, Healthwatch**

Patients supported the ReSPECT form as a vehicle for ensuring their wishes are recorded.

## Patients are individual people

- Patients want the right to make personal requests - whether it be drinking champagne, reminiscing the past, receiving the football results, or having a pet close by.
- Patients want to leave legacy plans - e.g. their wishes for how children might be cared for, once the patient has died.
- Choice goes beyond death - patients want their spiritual beliefs and customs to be respected and incorporated into the funeral ceremony.
- Patients want assurance that the system allows for diversity and difference; Discrimination should not be a factor in death and dying. This request was strongly held by patients within the LGBTQ+ communities; It also extends to religious communities; and those patients without capacity to plan or provide consent for example patients with learning disabilities or dementia.
- Patients want more openness when it comes to talking about death and dying. Some non-British cultures are more comfortable with this topic and this allows more opportunity for families to openly discuss end of life plans.

Patients want “the key issues [to be] about people as people.”  
Fran McCabe, Healthwatch Brighton & Hove

It was recognized that plans made in advance may not always be realized when met with the reality of the patient’s medical needs and/or the capacity of family members to be able to care for them at home.

## Patients want to be treated with dignity and compassion

- Patients want to be treated with compassion, kindness, and empathy from those around them: Professional staff, loved ones and informal carers.
- Patients want to ensure their wishes are not overridden by others, including loved ones.
- Patients want a dignified process not an event.
- Patients want to be assured that they will be remembered beyond death, even when they live alone or are in a care home.

“Patients need to be touched and spoken to at the end of their life - this is often the last thing they will remember.”  
Li Mills, End of Life Companion (Doula)

## Patients want good quality of care

- Wherever treatment takes place, home or elsewhere, patients want to ensure they receive good quality of care, including adequate medication to control symptoms and to not die in pain.
- Professional staff working with End of Life patients require support and training too - their emotional wellbeing needs to be cared for. An example of this is Advance Care Planning Training.

While not a focus of this webinar, paediatric nurses present in discussions highlighted that End of Life unfortunately affects the young as well as older people.

## 4. Questions and Answers raised in the webinar.

### 1. Where do you find out information about training as a Doula?

Doula training is based in Lewes through [www.lwdwtraining.uk](http://www.lwdwtraining.uk). (Li Mills)

### 2. Are the Death Cafes being run at the moment?

Death cafes are currently mostly online. There is at least one Brighton-based one coming up in June:

<https://deathcafe.com/deathcafe/11503/>

Li Mills who presented at the webinar is planning to start these up some time soon, in person (and outside). She can be contacted on [limills68@hotmail.com](mailto:limills68@hotmail.com) for information about this. (Li Mills)

### 3. How can the chaplaincy team link up with the Doula service?

Joanna Elliott, Lead chaplain for Brighton and Sussex University Hospitals NHS Trust, who attended the event and Li Mills (Doula) who presented at the webinar have already begun to have that conversation! If anyone would like to know more, please contact Li on [limills68@hotmail.com](mailto:limills68@hotmail.com). (Li Mills)

### 4. When was Version 3 of RESPECT introduced? Do we need to redo the form to have section 4 included?

Version 3 was first introduced in September 2020 and is currently being rolled out across Sussex. Version 2 can still be used. Please click on the link below for frequently asked questions on Version 3 for adopters (Dr Marian Messih):

<https://www.resus.org.uk/respect/respect-healthcare-professionals/v3-faqs-adopters>

Since 1<sup>st</sup> December 2020 the digital format has been available on the GP Practice systems across Sussex. Further information, a copy of the V3 and supporting information and leaflets can be found via this link. Wider communications about this form are planned in the very near future (Sarah Pearce):

<https://www.westsussexccg.nhs.uk/your-care/respect-plan-for-emergency-care-and-treatment/>



Any previous ReSPECT versions are still valid, but any updated conversation will require completion of a new version. ReSPECT is a process and as situations change then the information contained within the ReSPECT form should be updated. (Sarah Pearce)

**5. What is the feedback from patients/family re: ReSPECT - generally do people think it is a good thing or scary?**

In my experience feedback is very good. some people find it scary at first and aren't ready for the conversations but it's an ongoing process. (Dr Marian Messih)

It is still early days for Sussex, so we don't have any local feedback yet. However, nationally it has been well accepted. (Sarah Pearce)

**6. Is there any systems in place to assess if RESPECT and ACP have been successful to ensure that people's wishes for their End of Life, have been met by the people responsible for these. For example, does anybody look at the people in care settings who have completed RESPECT , and to review if these plans have been checked / executed?**

In the community our ReSPECT forms are audited yearly on content, completion and result (ie if the wishes of the person were upheld where able) (Lisa O'Hara)

In ESHT, East Sussex we audit preferred place of care/death i.e. where patients have recorded this preference, did they achieve their preference(s). We also look at, if not, why not. This was a key feature/priority for our recent CQC End of Life Care inspection. We also audit ReSPECT documents annually both in terms of quality of completion/was the person's wishes upheld. (Sue Lyne)

**7. I wonder if Quality Monitoring Team of local authorities also do audits on Respect / ACP execution with their annual inspections of registered care services.**

The B&H Quality Team do not audit ReSPECT/ACP execution as part of annual inspections. Providers are risk ranked re quality concerns. They do, however aim to complete a desk top review every 30 months where policies and procedures would be requested. (David Brindley, Ageing Well/Dying, BHCC)

**8. Can a DNACPR be set up without a patient's consent? Or can they be withdrawn?**

The patient should be involved in DNACPR decisions (unless considered harmful). Family, friends, Next of Kin and advocates should be involved if the

patient lacks capacity but ultimately it is a medical decision. Please click on the link below to read further about this (Dr Marian Messih):

<https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/> In particular, attention is drawn to the sections entitled “A doctor decides in advance” and “How long does a DNACPR form last”.

A DNACPR or ReSPECT form can be withdrawn and updated should the individuals situation change. (Sarah Pearce)

9. As an advocate with Power of Attorney, I found that even then this was not listened to, so how do we ensure that advanced care plans and POA are properly taken into account in all settings.

The process of conversation and documenting in tools such as Advanced Care Plans and ReSPECT should act as a prompt to check if a POA is in place and for the details of these to be recorded. In each clinical settings where decisions are being made about an individual’s treatment and care then these documents should be taken into account.

Part of the ReSPECT training being rolled includes how to ensure that these conversations undertaken are appropriately reflected and documented and are available to support future decision making.

10. Sarah, can these companionship projects at the hospitals you mentioned, also be made available to residential care settings?

The project mentioned was in Worthing Hospital and has been interrupted by the pandemic. The pilot has been run by the Hospital Chaplain so I’ll feed this thought back to them.

## 5. Taking this work forward

Healthwatch Brighton and Hove will continue to keep this issue on all agendas:

### **Brighton & Hove End of Life Steering Group**

We have a place on the Brighton & Hove end of life steering group at the Sussex University Hospital Trust and we will continue to raise the issues about:

- Quality of care;
- A dignified death;
- Roll out of ReSPECT;
- Training for staff and support and
- Involvement of families and carers.

We have already met with the Chief Nurse and Lead Consultant for End of Life about taking forward “A Good Send-Off, One Year On” and agreed the issues will be picked up in the Steering Group.

### **Dying Well Programme**

We will ensure appropriate issues are picked up in the Dying Well Programme which is monitored at the strategic and interagency level by the Health and Wellbeing Board. We have already flagged this and will continue to advocate for more attention on this aspect of care.

We will keep the issues raised by participants in the webinar on the Dying Well Working Group agenda. ( Who is on this)

### **Commissioners of Services**

We will continue to provide evidence and insight to ensure services are commissioned that support people in the community at the end of their life. In particular, a 24/7 service for people who are having palliative care to avoid unnecessary hospitalisation and to ensure a comfortable and pain free death and support for families.

We would also like to ask commissioners to gather quantifiable evidence from a medical perspective of what is an ‘unnecessary hospitalisation’. We would like to have a clearer understanding of why carers and informal carers make an emergency call or bring the patient to hospital.

### **Patient Experience**

We will continue listening to people about their experiences and what they want at the end of life. We have meetings set up in respect of trans people. We are conscious that cultural and religious issues have not been adequately addressed and we will ensure these remain part of all conversations. We are aware our work has focussed on adults and we are looking at options to include young people in the end of life conversation. When COVID restrictions allow, we will continue talking to people who are at the end of their life so we can feed back those experiences to health and care services for development and improvement.

## 6. Signposting - useful information and relevant people to contact

A

[Advance Care Plan \(sussexcommunity.nhs.uk\)](https://sussexcommunity.nhs.uk)

[Advanced clinical practice - NHS Employers](#) (EoL training appropriate to care home staff and anyone working with EoL patients)

[Ageing Well Service](#)

[Age UK | The UK's leading charity helping every older person who needs us](#)

[Alzheimer's Society](#)

[Arkafunerals.co.uk](https://arkafunerals.co.uk) (Funeral Celebrants including Li Mills)

B

[BSUH Chaplaincy team supporting staff and patients - Brighton and Sussex University Hospitals NHS Trust](#) (Joanna Elliott)

[www.brighton-hove.gov.uk/bereavement-support](http://www.brighton-hove.gov.uk/bereavement-support)

C

[Care for people who are dying | East Sussex County Council](#)

[Companion Voices - England UK - Singing for the end of life](#)

[Companion Voices Brighton - Natural Voice Network](#)

D

[Welcome to Death Cafe](#)

[Dying Matters](#)

E

[ECHO - End of life care hub \(sussexcommunity.nhs.uk\)](#)

End of Life Doula UK: [www.lwdwtraining.uk](http://www.lwdwtraining.uk) [www.eol-doula.uk](http://www.eol-doula.uk)

[www.facebook.com/lwdw.uk/](https://www.facebook.com/lwdw.uk/) @livingwelldying

[End Of Life Doula UK: For Learners on Vimeo](#)

[End of life games | Dying Matters](#)

F

[Funeral Guide - The Funeral Director Comparison Site](#)

[Frailty-practitioner-service](#)

H

[Find a hospice | About hospice care | Hospice UK](#)

I

[Independent Lives](#)

Independent Lives is a user-led charity. We work with people with support needs and carers, to enable people to lead full, active and independent lives.

L

Li Mills, End of Life Companion (Doula) and Funeral Celebrant,  
[limills68@hotmail.com](mailto:limills68@hotmail.com);

M

<https://www.martlets.org.uk/>

[Mycaresmatters - Improve the experience of a hospital stay](#)

P

[Palliative care - Brighton and Sussex University Hospitals NHS Trust \(bsuh.nhs.uk\)](#)

[Play cards and spark a meaningful conversation \(mariecurie.org.uk\)](#)

[Power of attorney - Lasting, enduring and ordinary | Age UK](#)

R

[ReSPECT Form | End of life care \(eolc.co.uk\) ReSPECT | Resuscitation Council UK](#)

S

[Home - St Michael's Hospice \(stmichaelshospice.org.uk\)](#)

[St Peter & St James Hospice](#)

<https://www.sussexcommunity.nhs.uk/> (includes search function and from here various links to EoL services and support)

## 7. Thank you's for the event

"Thanks Marion, really thought-provoking presentation."

"Well done Li. A great advocate for the privileged work we do."

"Thank you - so emotional to listen to."

"Thank you everyone for a very moving and important webinar!"

"A most enlightening and inspiring webinar."

"Excellent session, agree we are just at the start [of the conversation]."

"Lots of food for thought."

"Thanks everyone for their valuable insights, it's been informative and inspiring, and I will share with my colleagues who wanted to attend, but were working."

"excellent opportunity to discuss End of Life aspirations and issues."