



# End of Life Care in Cornwall

A report on public understanding and experience

November 2018









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## Perspectives for thought...



*At the opening of Healthwatch Cornwall's My Life My Death Conference in May 2018, health and care professionals were asked to share one word they felt represented end of life care in Cornwall currently.*

"I want our system to be responsive and caring to the dying person and their family so they do not feel alone or frightened and feel cared for and supported... Our aim is for Cornwall and the Isles of Scilly is to become a compassionate county that provides support to someone who is dying...this means a culture shift to normalise death, dying and bereavement and requires change from individuals, communities, services, organisations and systems"

*Dr Tamsyn Anderson, Chair of Cornwall and Isles of Scilly's End of Life Strategy Board:*

"I believe that we should all be able to choose how and when we die if there is no chance of a recovery to the point of enjoying life. I never want to be a burden to my family or the health and care services. It seems to be that there is a consistent lack of joined up thinking about EOL care mainly because we don't discuss it often enough in the public domain. Hopefully, this will be the beginning of a change."

*Respondent to Healthwatch Cornwall's End of Life Care survey, April 2018*

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# About us

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Healthwatch Cornwall (HC) is an independent, publicly-funded organisation. We have statutory duties and a remit to ensure health and social care services in Cornwall are the best they can be for people, now and in the future.

By listening to your experiences of publicly funded health and social care services we are able to inform decisions made by the commissioners and providers of them. This means your voice is heard by those planning and delivering services and can influence positive outcomes.



## VISION

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To inspire positive change in Cornwall's health and social care through effective public engagement.



## MISSION

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To make sure people's views and experiences influence decision making at the heart of Cornwall's health and social care.



## VALUES

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Independence, Inclusion, Collaboration, Credibility, Accountability and Sustainability

To see our strategy for 2018 to 2021 please visit:

<https://www.healthwatchcornwall.co.uk/wp-content/uploads/2018/09/Strategy-2018-2021Web.pdf>



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# Background

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In September 2017 Healthwatch Cornwall (HC) began to evaluate the impact our End of Life (EOL) Conference “A Good Death”, held in January 2016, had made on EOL care in Cornwall, just over 18 months after the event. The findings and recommendations in this report were produced as a result of the programme of work that arose from this evaluation.

At the time of the evaluation, we were conscious of three other important factors:

- The Care Quality Commission, the regulator of health and social care, had rated EOL care at the Royal Cornwall Hospitals Trust (RCHT) as ‘Inadequate’.
- We had received a number of accounts of poor experiences of EOL care in Cornwall, some of which were very concerning.
- Within Cornwall’s Health and Social Care Sustainability & Transformation Plan - known in Cornwall as ‘Shaping Our Future’ - EOL care was not assigned a dedicated work stream, given that EOL crosses many areas of care.

However it is well recognised within SOF that improvements in health and social care service provision at EOL, will improve outcomes and experiences for patients and families. This would result in better access to health and care when needed - where people wish to receive it. It would reduce unnecessary hospital admissions and re-admissions and result in better coordinated care, alleviating pressure within the system and ensuring a more effective and appropriate flow of patients through health and care services.\*

Therefore, HC committed to reviewing progress against previous work undertaken and to renewing our focus for EOL care work in Cornwall to ensure its priority across the wider health and social care system.

To support this work plan, we took our evaluation to the Cornwall and Isles of Scilly End of Life Strategy Board (C&IoS EoLSB) where consideration was given to how we could usefully contribute to the improvement of EOL care across the county. This led to a programme of work in early 2018.

## Cornwall & Isles of Scilly End of Life Strategy Board key priorities:

1. Raise public awareness and EOL education and training.
2. Improve EOL care planning in advance.
3. Ensure people and professionals can access the right care and support at all times of day and night.

\*End of Life Care, Sustainability and Transformation Partnership Support Tool, Cornwall and Isles of Scilly, October 2017. NHS England Gateway Number: 07152





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## The C&IoS EoLSB agreed HC was uniquely placed to:

1. Host an interagency EOL conference for professionals from across the health and social care sector (supporting key priority 1).
2. Conduct research into public understanding of EOL terminology, options available to people and their preferences for EOL care. This would help to provide a baseline of public knowledge and understanding from which any future public education could be measured (supporting key priorities 1 and 3).

### HC 2018 EOL Conference:

With these objectives in mind, in May 2018 HC hosted a second EOL conference for professionals: *My Life, My Death*. The ethos of the day was aligned to our mission, vision and values. While the aim of the conference was to provide an educational update and learning for a wide range of professionals (in line with key priority 1), the conference brought many other benefits to those who attended. It enabled us to: support interagency working, to nurture relationships with existing professionals and engage with new ones, and to raise our profile among health and social care professionals. Furthermore, the success of the conference has led to our decision to host an annual event for professionals with a patient centred theme, on a health and social care area of current public and professional interest.

### HC 2018 EOL Research:

To conduct the research promptly and enable us to share the findings at the conference in May, we worked with a national health and education specialist research agency, Alterline. In collaboration with Cornwall Hospice Care we used this opportunity to find out more about people's experience of losing a loved one and of bereavement services in Cornwall, to help shape and inform how support and services should be delivered. Cornwall Hospice Care is a charity that helps people with a terminal illness. Their clinical teams support patients at hospice buildings in St Austell and Hayle, in hospital at RCHT, in care homes and in the community through their 'Neighbourhood Hubs'. They also run a 24 hour advice line offering guidance to healthcare professionals.





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*Gina Starnes, Community Engagement Project Manager, Cornwall Hospice Care:*

“The world of palliative care is always evolving and Cornwall Hospice Care is adapting to meet the needs of future patients, many of whom are determined to be cared for at home. Our vision is for all people living with a terminal illness in Cornwall to be able to access the care and support they may need at the time and in the place that is right for them and their families... We are pleased to have been involved in the research undertaken by Healthwatch Cornwall, as it is really important for us to understand the needs of our population in order to plan our future strategy and service.”

HC in partnership with Cornwall Hospice Care, also produced an Advance Decision Card. This can be carried by individuals to let people know they have documented their wishes in an Advance Decision form, <sup>1</sup> (also known as a ‘living will’) should they suddenly lose the capacity to express themselves following an accident or sudden illness. Following the release of this report, a campaign will follow to promote the use of the Advance Decision Card and form, and to encourage the public to have conversations about their wishes for EOL.

Our focus on EOL care at Healthwatch Cornwall is now firmly embedded within our 2018 to 2021 strategy, with EOL care being one of our nine key priority areas.

Our work has now been consolidated under the title “My Life, My Death” (MLMD), as part of our on-going commitment to raise awareness and influence positive change in EOL care in Cornwall.

• <sup>1</sup> <https://compassionindying.org.uk/library/advance-decision-pack/>



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# What we did

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## My Life My Death Conference

Healthwatch Cornwall hosted the ‘My Life - My Death’ EOL conference on 17 May 2018 to coincide with ‘Dying Matters’ Week (14 to 18 May 2018).

The conference brought together professionals from statutory, private and voluntary sectors within health and social care. We focused on improving the experience of patients and those close to them through a varied and interactive agenda which comprised of:

- Educational updates from speakers, films and a ‘live show about death’.
- Research and evidence based on local people’s experiences.
- Workshops and interactive opportunities for professionals to learn from colleagues across a range of disciplines.

The objectives of the conference were founded on delivering a more patient centred approach to EOL care in Cornwall which included:

1. A review of progress against the recommendations from ‘A Good Death’ held in 2016
2. Sharing best practice, education and training for professionals
3. Sharing HC’s EOL care research results
4. Outlining further work required to improve people’s experiences of EOL care in Cornwall

Our My Life, My Death (MLMD) conference was attended by nearly 100 delegates from 36 different organisations. The day was centred around individual stories and the importance of having conversations about death and dying. We launched HC’s short film “Maggie & John’s story”, in which Maggie Vale bravely recounted the recent loss of her husband and the care they received that did not meet the standard of EOL care we should expect. The audience learned about progress to date on our 2016 “A Good Death” report’s recommendations from the Chair of the C&IoS EoLSB, Dr Tamsyn Anderson. We shared the key findings from the MLMD research, the aim of which was to evaluate the public’s awareness and knowledge of EOL care, people’s options and preferences. Lynne Dunn from the South Western Ambulance Service NHS Foundation Trust (SWAST) updated the audience on their Cancer Care Development project. The ‘Outside the Box’ show provided unique insights into a range of experiences of death and dying delivered with “grace and humour.”



During the second half of the conference, a range of organisations and professionals hosted 10 different discussion tables (repeated over three workshops) on areas of professional interest - some of which expanded on earlier presentations and others aimed to spark creative discussion and allowed participants to share best practice. The detail of these presentations and key points from the workshops can be found in the 'Conference - Summary of Presentations and Workshops' section of this report.

The spirit of the conference was creatively captured through graphic recording by Inky Thinking and is illustrated in full at the beginning and throughout this report.

### My Life My Death attendee comments:

"A great day to meet with professionals, exchange experiences and hopes.  
Please offer another event in a couple of years at latest"

"It was very encouraging and hopeful to learn how much is being done to improve EOL Care in Cornwall and I hope this spreads across the county"

"I learnt a lot that I can feedback to CAP, KCCG communications team, PPG etc"







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## Our EOL Research:

In collaboration with the C&IoS EoLSB and Cornwall Hospice Care we conducted our EOL research to gain an understanding of people's views and experiences from across the county. Working with health and education research agency Alterline, we developed the survey for which we received nearly 700 responses (665). We are grateful to the people of Cornwall who have supported us in gathering much more than data and statistics. People have generously shared a wealth of touching, personal stories and experiences which have informed our recommendations, and will continue to shape our work in the future. Key findings from the EOL research are published within this report, with the full presentation delivered at the conference available via our website under 'Our Work'<sup>2</sup>.

As part of our commitment to raising public awareness about people's wishes at the end of their lives, HC committed to developing an Advance Decision Card to support key priority 2. Very quickly we learnt that Cornwall Hospice Care were developing something similar as part of a campaign with Young Farmers in Cornwall (Pass it On)<sup>3</sup>. We decided to work in partnership sharing production and distribution costs to enable us to reach as many people as possible. The card, and the Advance Decision plan - the vital documentation that supports the card, is now available from HC, at our engagement events around the county, on our website and at Cornwall Hospice shops across Cornwall.

## Acknowledgements

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Healthwatch Cornwall would like to thank its dedicated team of volunteers who supported this project and helped to spread the word about the work we do. We would particularly like to thank Mrs Maggie Vale who bravely shared her personal story of the loss of her husband John, captured in our film, 'Maggie and John's Story'.

We are appreciative of the collaborative approach in working with colleagues on the Cornwall and Isles of Scilly End of Life Strategy Board and at Cornwall Hospice Care, the conference presenters, workshop hosts and the fantastic charities who exhibited with their stands at the MLMD conference.

Finally, a very big 'thank you' to the people of Cornwall who took the time to share their experiences and thoughts in our EOL research, on what for many would be an incredibly personal and emotive subject.

• <sup>2</sup> <https://www.healthwatchcornwall.co.uk/our-work/>

• <sup>3</sup> <https://www.cornwallhospicecare.co.uk/our-care/pass-it-on/>



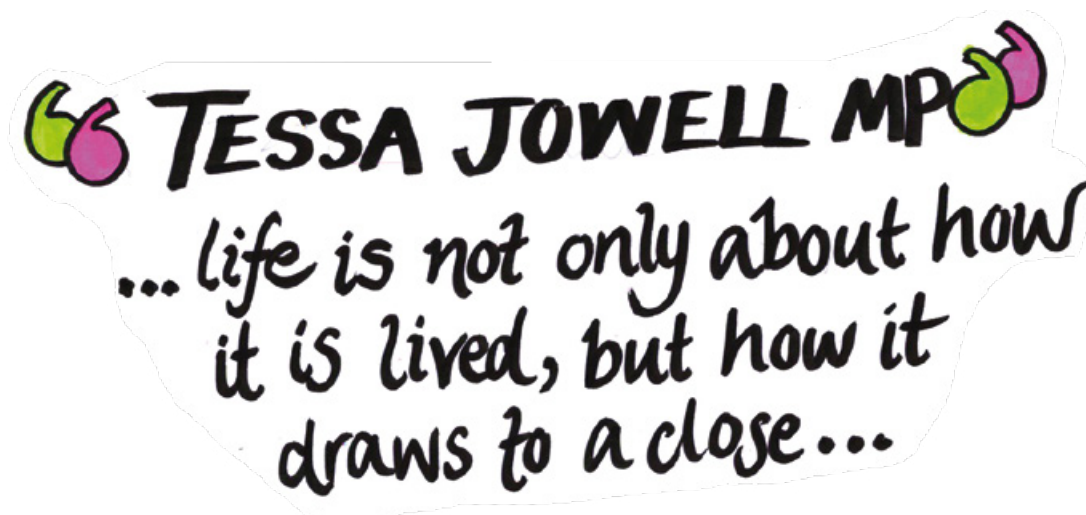
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## Executive Summary

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### Healthwatch Cornwall's EOL Research and My Life My Death Conference

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This section of the report draws together the learning from the My Life My Death conference and the EOL research conducted in April 2018. We have included some of the comments and stories people provided through our EOL research.

An overarching, clear message as a result of this work is reflected through our continued focus on EOL care in Cornwall and in our 2018-2021 strategy at Healthwatch Cornwall. Our ambition is to ensure people in Cornwall experience the best possible end of life care that meets their wishes and needs. We want people to receive high quality care, delivered compassionately and with dignity, by the right person, with the right skills at the right time. By doing so, we hope this will ensure people at the end of their lives and those close to them, will experience a calm, peaceful and dignified death where possible. We want to promote a compassionate county where carers and families are supported through terminal illness and bereavement, whenever they most need it.



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## Key Findings:

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### Public Education and Information:

- There was a call for a cultural shift to de-medicalise death within our society and enable better EOL planning: currently, very few people have an EOL care plan.

“I am young (ish) so end of life planning isn’t something I have thought about yet and I’m not sure I’d know where to go to ask about planning for my end of life, whether medically or financially. It would be good to have a site where you could go online to get the answers, all in one place.”

- People should be encouraged to talk about what care would be preferred at their EOL, and to document their preferences.

“I feel that death is not discussed enough. It is a process everyone goes through but people do not plan for it, there is such fear around death and if people were more aware about the process of dying then this fear could be dispelled and people may understand that a good death free from pain, distress or agitation can be a beautiful moment. I feel passionately that people should be supported to have a good death and their wishes respected up to the end and beyond their death.”

- People’s understanding of the language used in EOL care varied and technical terminology was not as well understood.
- The public need to know more about the choices that are available to them for their EOL care, the practical and legal processes following death and about the breadth of options for funerals and burials.

“My Mum requested a cardboard coffin as she was having a green burial. The funeral director was not happy to provide this and we were made to feel that he didn’t approve. We went ahead anyway, as her wishes were important. She had a beautiful funeral that she would have been proud of and is buried in a meadow...with her cardboard coffin.”





- Families, friends and GPs were the main providers of support to those with a terminal diagnosis and as such require the right skills and resources to be well equipped to provide this.
- We need to increase support for carers and supporters of those with a terminal illness and for the bereaved. Services need to be well publicised, easily found, offer different approaches and in different formats (online, digital, face to face).

### People's Wishes:

- People wanted to die in their preferred setting, where delays to good care, equipment and access to services were minimised. Most people preferred to die at home, with care that provides comfort, is dignified and pain-free, at all times of day and night.

“End of life care should be tailored as much as possible to the individual... A person should be able to make a decision about their own treatment, whether they want to be at home, in hospital/hospice and who they want around them...”

- People wanted to receive a terminal diagnosis in the right place, at the right time, delivered by the right person, in the right way.

“Prognosis should be delivered sensitively at diagnosis, with a longer appointment time for this. An early follow up appointment should be offered, not waiting weeks or months as now, where more opportunity to be made aware of the pathways available and the practical, emotional and psychological issues ensuing from such diagnoses.”



- People wanted to be communicated with in a way they could understand. Checking people's understanding was key - whether patient, carer or family.

"...Families should be informed of any and all changes in a person's well being and be given the chance to say goodbye in the way they see fit..."

### People's Experiences:

- There are examples of great EOL care and good practice across Cornwall:

"The palliative care nurse and the staff at the hospice who nursed him during his final two weeks of life were absolutely superb. They allowed me to revert back to being a wife rather than a carer and he felt safe in their compassionate care. I can't thank them enough for giving us both such a wonderful end-of-life experience."

- However the need to improve people's experiences of EOL care in Cornwall was evident:
  - People's satisfaction with how a terminal diagnosis was delivered was low (40%).
  - Only one in two bereaved were satisfied with the quality of care their family member received during their end of their life, and 29% were dissatisfied.
- Patients and family members' understanding of a terminal diagnosis was low (31%), despite two thirds feeling they had the opportunity to ask questions. A terminal diagnosis was most often delivered by a hospital doctor (63%) or a GP (13%).
- There were perceptions and experiences that: it is difficult to access hospice care, it is difficult to arrange dying at home and there are financial barriers to care.



“We need many more hospice places...Care homes were too depressing but the hospice was lovely, however we were warned there were few places and one was unlikely to be available.”

- Carers and supporters of those with a terminal illness were regularly providing emotional support and care. Despite this, one in two ‘carers and supporters’ were not getting the support they needed.

“We had a bad experience all round when it came to support, felt really let down constantly chasing up things, being given incorrect info and everything just seems to be money led.”

- Almost half of the bereaved did not feel they had enough support, with a particular gap in support identified between the six and 12 months following bereavement.
- Most commonly, people wanted more help and information regarding matters such as private, legal and financial affairs.

### EOL Care Provision:

- Areas of the ‘Ambitions for Palliative and EOL Care’<sup>4</sup> framework that performed least well, were: ‘each person gets fair access to care’ and ‘care is coordinated’.

“Support needs to be more available in the community, there are not enough care agencies to cope with the demand. This results in people who want to die at home being stuck (and so bed-blocking) in hospitals and hospices.”







- We need to increase the number of people identified as at EOL.
- People on the EOL register should have a plan when discharged from hospital/hospice.
- There needs to be better liaison between health and social care, and between multi-disciplinary teams, in order to deliver patient-centred care. This should include the use of shared care plans.
- We need to ensure communication is regular and effective, and documentation is shared between professionals and with families before and after death, so people at all stages understand what is happening.

“The doctors in hospitals do not know their patients or their history. They need to listen to relatives more closely and make sure all info is passed on to each subsequent shift.”

- We need to identify and recognise specialist skills and services, encourage outreach and in-reach of hospice specialism and ensure clinicians are aware of the expert support they can access.
- All services should work in partnership with other sectors in order to share ideas, reduce duplication and time wasting.

“Care packages need speeding up - we got into considerable debt whilst waiting over 6 months for it to come in”

- Professionals and care providers need to ensure the use of treatment escalation plans is embedded into practice.
- The future provision of electronic care plans was well received. Building trust in the product was seen as key. Successful implementation will require engagement with staff and the public, effective training and product testing.
- People with learning disabilities or autism need person-centred care plans, appropriate and factual language, social stories, interactive and engaging tools, and to be offered on-going support, whether receiving EOL care themselves or experiencing bereavement.
- We need to be more mindful of fluid intake when treating and caring for people at the end of their lives and could consider tools that enable professionals, carers and family to do this.

• <sup>4</sup> National Palliative and EOL Care Partnership, (2015). Ambitions for Palliative and EOL Care A National Framework for Local Action 2015-2020. Available at [www.endoftifecareambitions.org.uk](http://www.endoftifecareambitions.org.uk)



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## Education and Training for Professionals:

- There is a need to provide better training for all aspects of communication of EOL care, from delivering a terminal diagnosis through to bereavement support.

“...She is talked over by family, doctors and carers and not included in decisions nor included in information given by doctors. I don't want this to happen to me!”

- Professionals need to check people's understanding (the patient and those close to them), and ensure they have a clear understanding of what is happening and the next steps.
- Staff need to feel empowered to challenge decisions of fellow health and care professionals and to not make assumptions. This may require a shift in culture.
- The Medical Certificate for Cause of Death form is not always being completed 'right first time'. Further training is required to address this and to improve clarity on reporting. Training should also include verification of death and cases requiring a post-mortem.

“My GP wrote out the Cause of Death Certificate wrongly giving me even more stress after the death. The Registrar was very helpful but I had to visit twice because of the GPs mistake and was very stressed. The funeral director had same trouble, nearly had to cancel the funeral.”



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# Recommendations

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Healthwatch Cornwall propose the following recommendations, which we have aligned to the Cornwall End of Life Strategy Board's three priorities:

## Priority 1. Raise public awareness and provide EOL education and training:

1. There is a call for change within our community to de-medicalise death and to normalise dying and bereavement. This requires a concerted effort to drive a cultural shift, by engaging individuals, communities, organisations and systems. The system should work together to develop a strategy to achieve this.
2. Educate the public and encourage people to make informed choices to ensure we can deliver personalised EOL care.
3. Training for professionals should ensure all communication is effective and appropriate (right place, right time, right way) and checking people's understanding is crucial to this.
4. Professionals require training and up-skilling in:
  - Delivering a terminal diagnosis
  - Effective communication
  - Completing the Medical Certificate for Cause of Death
  - Knowing when a coroner needs to be involved

## Priority 2. Improve EOL care planning in advance

5. The system should promote the uptake of personal EOL plans and support individuals to make plans in advance, using tools to document wishes, such as the Advance Care Plan.
6. Providers should ensure liaison between health and social care services and within multi-disciplinary teams means the patient experiences a smooth transfer between services and continuity of patient-centred care. Shared care plans promoting partnership working are essential.

## Priority 3. Ensure people and professionals can access the right care and support at all time of day and night:

7. Ensure EOL care meets people's wishes, is dignified, as pain-free as possible, peaceful and comfortable, at all times of the day and night.
8. Enable EOL care to take place in an individuals' preferred place of dying.



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9. We need to improve the experiences of patients and families at the end of people's lives and demonstrate how their views are being used to shape service improvement.
  10. Providers should work together to target areas of the 'Ambitions for Palliative and EOL Care' framework requiring improvement, in particular:
    - Each person gets fair access to care
    - Care is coordinated
  11. Providers should, along with the voluntary sector, consider how they can address the need for greater support for carers of those with a terminal illness.
  12. Providers should ensure specialist skills and services are promoted and are accessible by clinicians and the public to enable specialised EOL care to be delivered when and where it is needed (in-reach, outreach, Neighbourhood Hubs etc).
  13. Services should increase their understanding of the different approaches and specialised resources those with a learning disability (receiving EOL care or bereaved), may require.
  14. Bereavement services need to be available, accessible, personalised and offered beyond the immediate bereavement period. Service directories, varying options and flexibility in timing and techniques are essential.

**Further to this:**

15. All services and providers should ensure their EOL strategies and action plans to improve EOL care demonstrate due consideration of the key findings and recommendations within this report.

## Next Steps and Further Research

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- To share this report and recommendations with commissioners, providers and the wider hospice and Healthwatch Network
- To share the questions, further comments and suggestions provided by professionals who attended the MLMD conference, with the C&IoS EOLSB in order to inform future plans
- To work with the C&IoS EOLSB to develop an action plan to progress all the recommendations
- For HC to continue making EOL care a priority throughout 2018 to 2021, maintaining a place on the C&IoS EOLSB
- For HC to conduct further research into carers needs in 2019
- For HC and Cornwall Hospice Care to plan a public campaign to promote advance decision planning





# My Life My Death Research

## Research Summary

Natalie Swann, Research Manager, Healthwatch Cornwall

Healthwatch Cornwall commissioned a piece of independent research with local people. The research supports the C&IoS Strategy Board’s work towards Priority One in the work plan by building a picture of public understanding and experiences of EOL care in Cornwall, as well as their wishes and preferences. The full presentation can be found on our website under ‘Our reports’<sup>6</sup>. Recruitment took place mainly through an online local research panel along with some promotion via social media during April 2018. A total of 665 people took the survey:



The research is presented under four respondent groups, based on people’s experiences.

The Public	Terminal illness	Carers and supporters	Bereaved
All people who took part in the survey (including those with terminal illness and bereavement experience)	People with a terminal diagnosis and family of people who have had a terminal diagnosis	People who consider themselves a carer (paid or unpaid) or a 'supporter'	People who have experienced a bereavement in their immediate family in the last two years
Section 1: Perceptions of end-of-life care	Section 2: Experience of terminal illness and end of life care	Section 3: Experience of caring and supporting those with terminal illness	Section 4: Experience of bereavement

Respondents often sat within more than one group:

- 9 (1%) — With a terminal illness
- 385 (58%) — With a family member with a terminal illness
- 285 (43%) — Carers of someone with a terminal illness
- 361 (54%) — Supporters of someone with a terminal illness
- 205 (31%) — People who had experienced a recent bereavement
- 159 (25%) — People with no experience of bereavement or terminal illness



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## Key findings from each section are as follows:

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### 1. Perceptions of EOL Care: We asked the ‘The Public’

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#### Do we talk about dying?

- Speaking to family and friends about EOL preferences was more common in those who had experienced terminal illness or bereavement (47% vs 21%).

#### Do people have EOL care plans?

- Very small numbers of people had an EOL care plan, whether they had experience of terminal illness or bereavement (5% vs 2%).
- Around one in ten told us they had an Advance Directive (a legal document which explains what treatment the person would want if they couldn't speak for themselves). There was a small difference between those who have experienced terminal illness or bereavement (12% vs 7%) and those with no experience.

#### What do the medical terms mean?

- The public's understanding of the terms and language used in EOL care varied, but was particularly low for technical terms such as ‘Treatment Escalation Plan’, ‘Advance Directive or statement’.

#### What is our preferred place of death?

- People's most popular preference for place of death was at home (78%): ‘with family carers’ or ‘at home with care from hospice staff’ being the two most popular choices and ‘in a hospital’ as one of the least favourite options. Despite this, recent data shared at the EOL Strategy Board meeting in June showed just over half (53.4%) of all deaths in 2017/18 occurred at their usual place of residence. Whilst Cornwall compares favourably against the national picture in this regard (14th by Clinical Commissioning Group), there is clearly still room for improvement.
- When reflecting on statements aligned with the ‘Ambitions for Palliative and EOL Care A National Framework for Local Action 2015-2020’<sup>7</sup>, the two areas that performed least well were:
  - Each person gets fair access to care
  - Care is coordinated

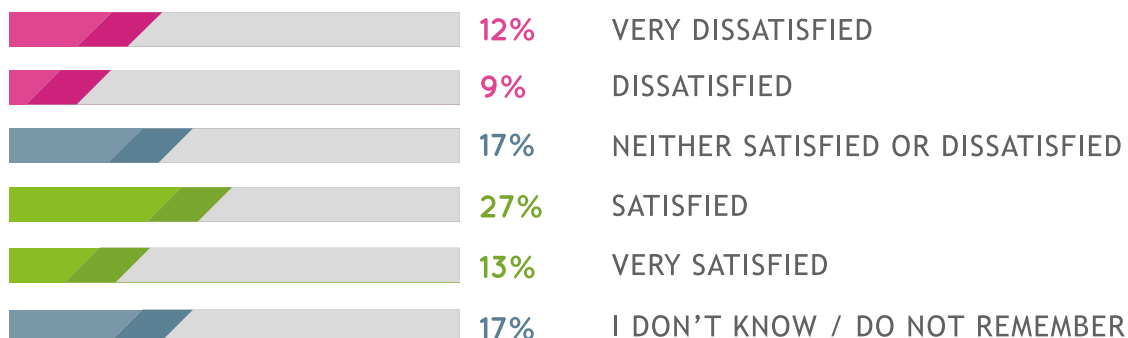
This is due to experiences and perceptions that: it is difficult to access hospice care; it is difficult to arrange dying at home (people often die in hospitals when they don't want to); financial costs can be a barrier to accessing care; pain-free and comfortable care is not guaranteed (the NHS is overburdened); and people have different experiences at different hospitals/with different GPs.

• <sup>7</sup> National Palliative and EOL Care Partnership, (2015). Ambitions for Palliative and EOL Care A National Framework for Local Action 2015-2020. Available at [www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk)





'SATISFACTION' WITH DIAGNOSIS IS VARIABLE: 21% DISSATISFIED - BUT ONLY 40% SATISFIED



- Despite two thirds (65%) having the opportunity to ask questions, only nearly a third (31%) understood what they were being told about their diagnosis.

### Are people supported with their diagnosis?

- Nearly two thirds (64%) received the support they needed when they were diagnosed with a terminal illness.
- Family (68%), GP (41%) and friends (33%) were the most common sources of support in dealing with a diagnosis.

### What does a good and poor experience of a diagnosis look like?

- Right place, right time, right person, right way, were all key elements of how a 'good' diagnosis was delivered.

"She was very straightforward about it, gave a possible time frame, didn't treat it as a drama, just an unfortunate reality, was encouraging about the time left to my mother."

"The doctor was kind, but straight to the point. He did not shy away from the truth of the matter."

- A 'bad diagnosis was: blunt and without compassion, rushed without opportunities to ask questions, without family present, when it was not necessary or asked for, without advice or next steps, or was too late.

"It wasn't explained fully or in a comfortable setting. I was told in a doorway to an office very briefly and very rushed. I wasn't asked if I fully understood what I was told."

"Not upfront about how much time and no advice on next steps."

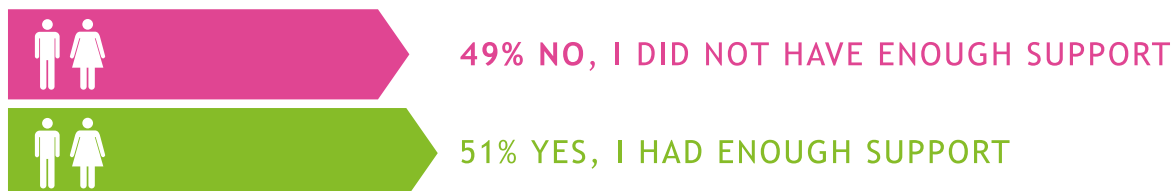




### 3. Carers and supporters of those with a terminal illness: Carers and Supporters

#### Are we supporting those who look after the dying?

- Almost half of carers or supporters of someone with a terminal illness did not feel they had enough support (49%).



“We received no support at all...Once he had his diagnosis he went downhill very quickly and we all found the lack of support very hard to deal with”

“...We were left to deal with all the fear and confusion ourselves”

“There was not enough advice given to me about his care or any assistance I could receive.”

#### Are we supporting those who look after the dying?

- Almost half of carers or supporters of someone with a terminal illness did not feel they had enough support (49%).
- Almost all carers and supporters were providing care or support more than once a week with a variety of tasks including household chores (62%) and personal care (58%), but most commonly, they were providing emotional support (85%).

### 4. Experience of Bereavement: Bereaved

#### Are we supporting the bereaved?

- Almost half of those who were bereaved did not feel they had enough support (48%)

“It’s all been such a muddle of financial and the emotional turmoil. It’s like a bomb exploded in our midst and we were all flung apart never to really find our way back together again. It’s the aloneness of all the choices and decisions, coping with breakdowns of people, homes, appliances, with only yourself to refer to. The absence of that lifelong partner and father to, is a huge emotional hole in our lives to this day”

*Bereaved respondent to Healthwatch Cornwall’s End of Life Care survey, April 2018*



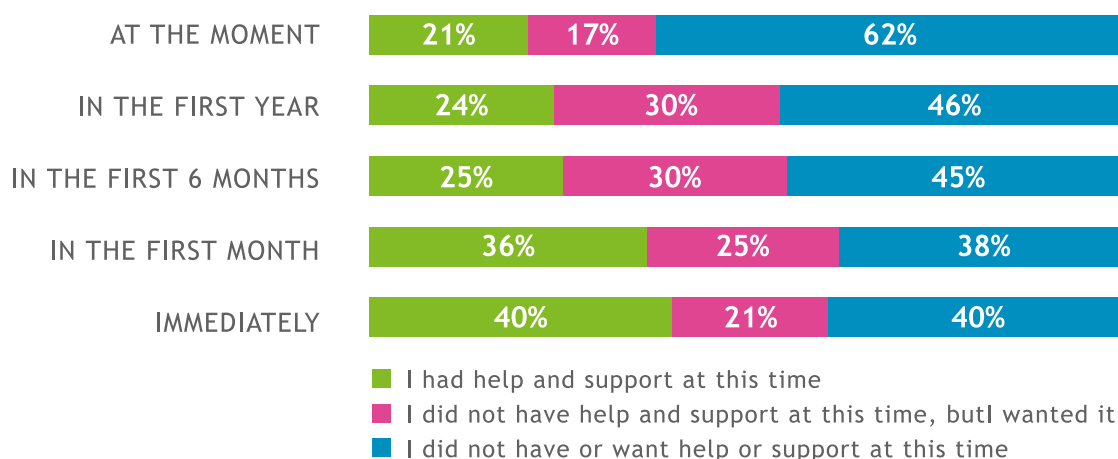
“The only support I wish I had had which wasn’t there would be having someone to speak to about the experience of being with someone when they pass away. Nobody asks and it’s not something you feel you can push upon someone else.”

“There is a huge gap left once caring is no longer needed because the friend or relative has died”

### What support do the bereaved need and when?

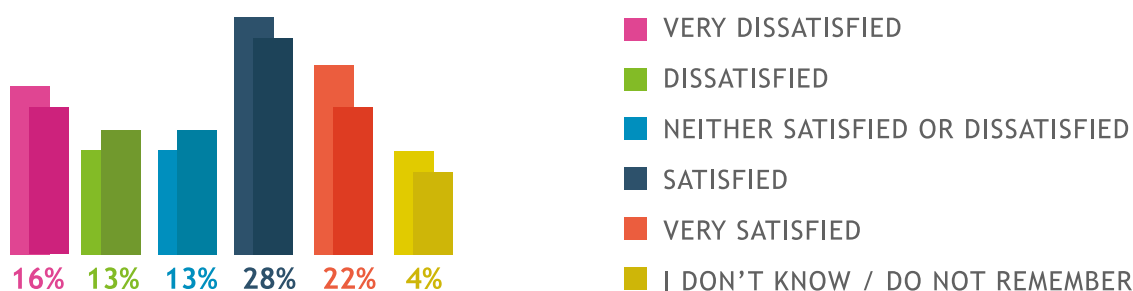
- There appears to be an unmet need for support following the immediate bereavement period: in the first 6 months and in the first year.

“More support needs to be offered to the family members who witness their loved ones dying and suffering. It’s an image that could stay with you a life time, every time you go to sleep and when you wake. Counselling should be standard and an open appointment for at least 12 months after the event, as some grief and be very delayed. It can come up and hit you like a freight train when you least expect and before you realise what it is, you are already drowning and that is when you will desperately need a life saver in support and counselling.”





- Around a third of people would have liked help with private, legal or financial affairs, more information, and support for carers.
- Family (67%), friends (56%) and the funeral director (35%) were the three main sources of support following bereavement.
- Only one in two people (50%) were satisfied with the EOL care their family member received and 29% were dissatisfied.



## My Life My Death Conference Summary of Presentations and Workshops

### Presentations:

#### Amanda Stratford CEO Healthwatch Cornwall and My Life My Death Conference Chair

Amanda welcomed delegates highlighting HC's aim for the individual and their story, to be central to the success of the day. As such, she opened the conference with the film HC had produced 'Maggie and John's Story', which recounted the recent experience of Mrs Maggie Vale and the loss of her husband John. Amanda asked delegates to keep this personal story in mind throughout the day.

Reminding attendees that there was a great deal of good practice in EOL care across Cornwall, it was made clear that it was our wish at HC, to ensure good care





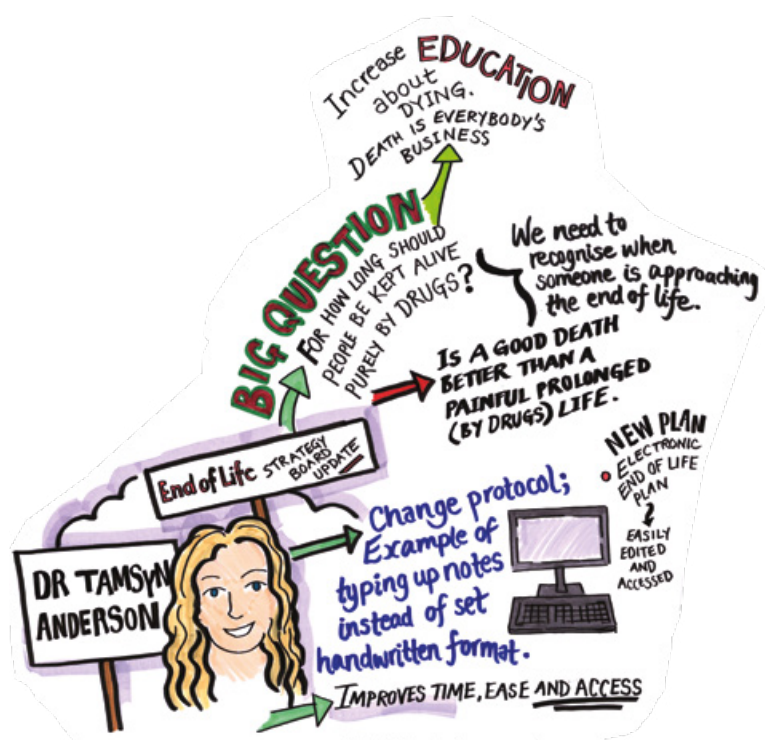
was available to all. Amanda took the opportunity to launch the Advance Decision Card which was produced collaboratively with Cornwall Hospice Care. She re-iterated the need for these to be used in conjunction with a completed advanced care plan and that people must let others know: when they have done this, where the plan can be found, and that it is a living document that requires updating.

(For more information on the Advance Care Plan, please visit the Compassion in Dying web pages<sup>[1]</sup>)

## Presentation: EOL Strategy Board Update

Dr Tamsyn Anderson, Director of Primary Care at Cornwall Partnership Foundation Trust, Chair of the End of Life Strategy Board and a GP in Newquay.

Tamsyn's impassioned opening comments reflected the Board's ambitions for improved EOL care in Cornwall:



“I wish to see us working together with patients and families to explore thoughts and fears around death to ensure we recognise EOL and make plans. I want us to be able to share this information as a system, so patients feel understood and supported. Most of all I want our system to be responsive and caring to the dying person and their family so they do not feel alone or frightened and feel cared for and supported.”

Dr Anderson provided a background to the formation of the Cornwall EOL Strategy Board, outlining how the Board was informed by key findings from previous Healthwatch Cornwall reports:

• [1] <https://compassionindying.org.uk/library/advance-decision-pack/>





### 2015 Healthwatch Cornwall ‘Place of Dying’ Report

- Importance of choice re place of death
- Timing of conversations
- Consideration of barriers to dying at home
- No pathway (information on support and choices to plan anticipated EOL care)
- Reduced support e.g. night sitting
- Lack of 24 hour care and shared paperwork
- Isolation and inequality reducing options

### 2016 Healthwatch Cornwall ‘A Good Death’

- To be heard/listened to
- To have family and friends present at the end
- To be pain free with symptoms managed
- To have co-ordinated streamlined care
- To be treated as an individual and with dignity
- To feel safe and to be “normal” as long as possible
- To have and be involved in a single care plan

## Background to the Board

Formed by a group of senior commissioners and provider representatives from across the health and social care sector, the EOL Strategy Board review the latest evidence and agree a system-wide vision and priorities. They develop work plans within their individual organisations, holding each other to account, whilst working collaboratively to understand the barriers to change and impact on the system when changes are proposed. This approach ensures a cultural shift from working in silos, to a more joined up approach to delivering the Board’s vision:

“Our aim is for Cornwall and the Isles of Scilly to become a compassionate county that provides support to someone who is dying...this means a culture shift to normalise death, dying and bereavement and requires change from individuals, communities, services, organisations and systems”

Developing compassionate communities and talking about death means discussing people’s wishes, such as dying at home, as without the discussion, people’s needs cannot be met. We need to ensure we are achieving NICE 2011<sup>8</sup> guideline standards of care where care is personalised, planned, coordinated and consistent:

• <sup>8</sup> National Institute for Health and Care Excellence (2011) EOL Care for Adults (NICE Guideline QS13). Available at: <https://www.nice.org.uk/guidance/qs13> [Accessed 26 07 2018].



- Discuss and plan: to develop and review a personalised care plan for current and future support and treatment.
- Experience coordinated care: delivered in accordance with their personalised care plan across all relevant settings any time of day or night.
- Experience consistent care: delivered by practitioners who are aware of their current medical condition, individualised care plan and preferences.
- Own a shared care plan: That is up to date and available to all professionals who deliver their care.

With this in mind, the Cornwall EOL Strategy Board priorities are:

1. To raise public awareness and EOL education and training
2. To ensure care is planned in advance and documented, where EOL care tools are used to enable this and monitored, such as:
  - Increased use of Treatment Escalation Plan as a tool to communicate a patient's wishes. (a TEP is a document the doctor completes following a discussion with the competent patient or close relative, to record the treatment options that would be appropriate, should the patient become acutely unwell)
  - Increased anticipatory prescribing - GPs can prescribe in advance to enable patients to receive prompt relief from any pain or distress, should symptoms arise
  - Electronic EOL register: Recent procurement decision agreed to deliver 'Coordinate my care', an electronic patient record for recording patient's wishes and ensures their urgent personalised care plan is accessible to all who care for the person.
3. Timely and appropriate response: At all times of the day and night, whether through general practice or out of hours services, individuals and families' needs should be understood and met. Further work to support individuals and clinicians to get this right needs to be done, such as raising awareness of the expert support clinicians can access.

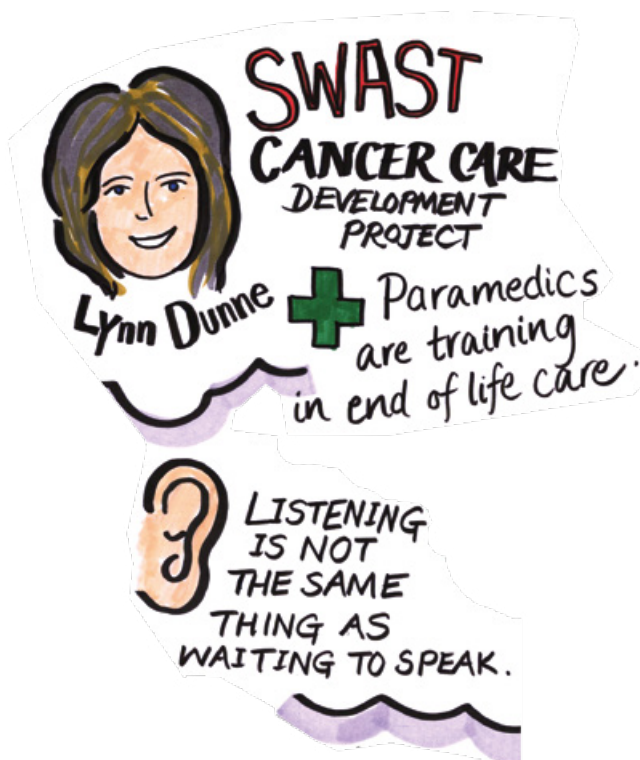
In conclusion, Dr Anderson summarised success factors as the following:

- Increased number of people identified as EOL
- Increase in multi-disciplinary teams discussing and planning EOL care
- Increase use of TEP forms
- Increase in personalised care plans in place
- Increased anticipatory medication prescribing
- Equipment delivered in less than 24 hours in every case
- Increased death in preferred place of care
- Reduction in admissions to the acute hospital in the last year of life
- Zero delayed transfers of care (DTC) at EOL
- Individuals and families reporting improved experience of care



## Presentation: Cancer Care Development Project

Lynne Dunne, Macmillan Cancer Care Facilitator (West Division)



As a wealth of research has identified (including Healthwatch Cornwall's most recent local EOL research), people want to remain and be cared for in their preferred place of dying - most often at home. Lynne Dunne presented a collaborative approach to emergency and palliative care between the South Western Ambulance Services NHS Trust (SWAST) and Macmillan Cancer Support. The specialist project teams' approach aimed to improve acute cancer, palliative and EOL care for patients in accessing out of hours care (when GP surgeries are closed) or urgent care (i.e. paramedic or ambulance) within the SWAST catchment area.

Helping EOL patients to remain at home required a shift in approach from a typical response of lifesaving and transporting the patient to hospital. In Cornwall paramedics are now familiar with the management of breathlessness in advanced cancer, as well as symptom control for patients in the last days and hours of life. This was made possible through the development and delivery of the 'Open All Hours' education day and Advanced Communication Skills Training. This was implemented in conjunction with the development of appropriate care pathways to enable paramedics to deliver the right care, at the right time and in the right place. For example, the project team developed Patient Group Directions\* for the 4 commonly used symptom control drugs at EOL. The aim of this work was to try and ensure that no palliative care patients or anyone in the last days and hours of life would suffer from poor symptom control or relief in the out of hours period, due to a lack of resources or necessary prescribed medication.

"We hope this will be a valuable resource to all patients, their families and carers in Cornwall."

\*Patient Group Directions enable a paramedic to give an approved drug to particular patient group e.g. patients in the last days and hours of life, if the specified safety criteria are met.

You can watch and learn more about this great work here: [www.youtube.com/watch?v=mMnv-\\_qoQc8](https://www.youtube.com/watch?v=mMnv-_qoQc8)



## Performance: Outside the Box

### Liz Rothschild, Celebrant and Actress

Liz, a celebrant, actress and award-winning burial ground owner performed her critically acclaimed show “Outside the Box”. Liz shared a collection of tales about EOL and of death, with humour and compassion. The stories from the show can be accessed from Liz’s website here<sup>9</sup>. Her approach encourages the audience to embrace death, to talk about it and to explore what is important to us. Liz also facilitated a workshop session where key findings from this are summarised in the workshop section of this report. A few examples and comments from Liz’s vast collection of varied and interesting stories she shared with the MLMD audience are below:



**Heart in Life, Heart in Death:** “Whilst the heart of the person stops beating, the heart of the person’s soul and wishes can be followed and should be. The symbol of love should be right to the end and beyond.”

**Cardboard Coffin:** “One of my dear friends chose a natural burial, and had a year to prepare. He bought his reinforced cardboard coffin, kept it in the garage for 6 months, and then decided to paint it with scenes of his life. A friend who was an artist joined in, so too eventually his neighbours, (who he did not know very well up to that point) and friends also added their artwork. It seemed to create a ‘melting’ in people, and a joy to do this. He was buried in this with the various artworks and messages painted on it.”

“The presentation piece by the actress was very interesting and made us laugh and think about death in a different way...”

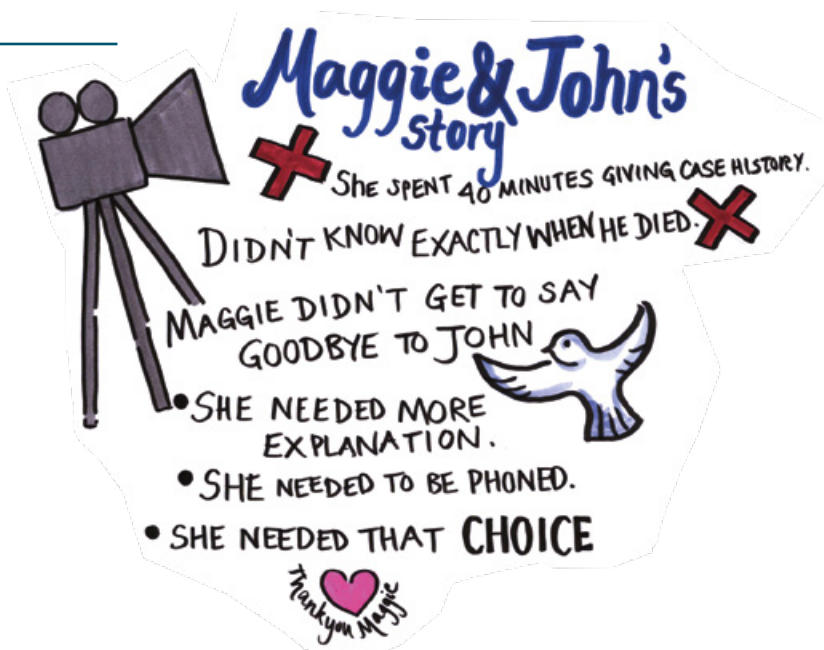
<sup>9</sup> <https://www.fullcircleproductions.org.uk/venue/eol-conference-eden-project-cornwall/>



## Film: 'Maggie and John's Story'

Featuring Mrs Maggie Vale

We were privileged to be able to work with Mrs Maggie Vale, to produce and launch a film at the MLMD conference in which Maggie shared her experience of the EOL care of her husband John, who died in early 2017. Maggie was keen to tell her story in the hope that it could lead to improved care for others. Maggie described that from September 2016 a catalogue of less than adequate support was given to her and to John. During John's final admission to hospital, Maggie said the doctor explained John was on a drip as he was not eating and had said:



“That’s all that’s keeping him going.”

However, it was not made clear to Maggie what would happen to John if the drip was removed.

“But I didn’t expect a call on the Friday morning to say that John had died in the night. And no one knew what time. I couldn’t believe they hadn’t kept an eye on him. I wish the doctor had indicated how long he might have left when not on the drip anymore...”

“We didn’t get the chance to say goodbye to John.”

Maggie strongly believes that people have a right to know what’s happening at the end of their loved one’s life.





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“If someone doesn’t want to know that’s their choice too, but there should be the option for a clear explanation of what’s going on.”

For Maggie, it is important that:

- Discharge letters are given to a person’s carer if applicable, perhaps even handed over from non-emergency transport ambulance staff
- There is more training for staff in dealing with end-of-life care to better support the patient and those close to them
- More consideration needs to be given to informing and involving families so they are fully aware of what is happening
- Liaison between hospital and social services is greatly improved.

Better communication, training and liaison between services were commonly identified themes for improvement in EOL care, in both HC’s local and also in national research.

The film ‘Maggie and John’s Story’ can be accessed here:

<https://www.healthwatchcornwall.co.uk/films/> and the case study notes here:

<https://www.healthwatchcornwall.co.uk/newsletters-healthwatch-cornwall/case-studies/> under Maggie’s story.

We also ran a workshop during the afternoon where further details from the discussion are captured below.



# Workshops:

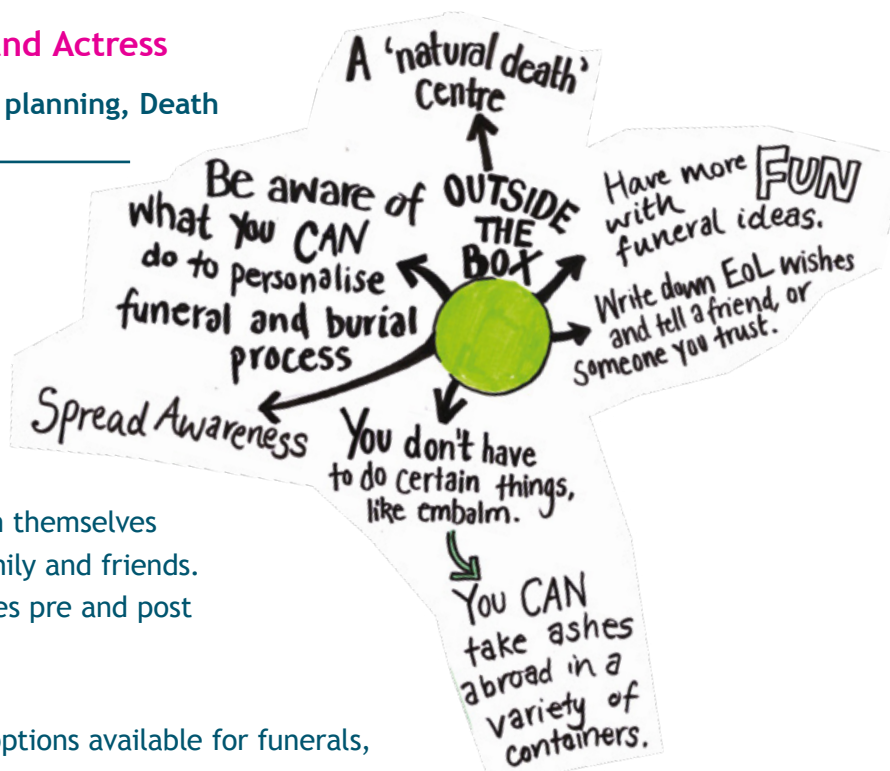
We ran 10 workshops where participants pre-selected 3 sessions to attend during the afternoon. A summary of the key points and priorities raised at each are as follows:

## 1. Liz Rothschild, Celebrant and Actress

Celebrancy, Green Burial, Funeral planning, Death

Liz Rothschild called for us to have fun with the idea of funerals, shop around for funerals, seek out independent funeral directors, visit a crematorium and understand your options for EOL and death:

- The public should better inform themselves and share their wishes with family and friends. Ask questions about your choices pre and post death and do your research.
- Offer more information about options available for funerals, burials, the legalities and processes for the body following death.



“This was a vibrant and practical discussion about death, which helped us all to re-frame the way we think about death and dying, the options, the practicalities. It helps you to see that there are different ways that funerals and burials could happen...we just need to think about what we want, what others may want and know that there is much more than just the ‘standard’ way. Very interesting!”

## 2. Sharon Mingo, Kernow Clinical Commissioning Group

Electronic Care Plans

In this workshop attendees discussed the practicalities of how “Coordinate my care”, an electronic patient record for recording patient’s wishes, could be best implemented across the system.

Key points were:



- Take care when transitioning from paper to electronic form.
- Engage with the public and staff, use demonstrations, provide training and communicate effectively.
- Test and build trust in the product.

“I am encouraged by the prospect of integrated record potentially improving our ability as emergency services to provide the most appropriate care”

### 3. Senior Coroner - Dr Emma Carlyon, Emma Hillson - Coroner Officer, Linda Warne - Bereavement Manager

#### Understanding Verification of Death

Key messages for professionals were:

- Not all cases referred to the coroner need a post mortem - contact the coroner if clarification required.
- Complete the Medical Certificate for Cause of Death (MCCD) forms right first time. Cremation may change things: verification and certifying could require extra involvement/signatories/time.
- Better communication after death between all parties is required - ensure families are involved at all stages.

### 4. Gina Starnes, Community Engagement Project Manager, Cornwall Hospice Care

#### How Can We Help Each Other To Support EOL Care In Cornwall?

Gina Starnes introduced Cornwall Hospice Care’s ‘Neighbourhood Hubs’ and the role community hubs can play in supporting the terminally ill, their carers and families. The Hubs bring the expertise of the hospice out into the community - and much earlier in the disease. The idea of Neighbourhood Hubs is to encourage patients and their carers to manage their symptoms, to



• Resource: <https://www.england.nhs.uk/wp-content/uploads/2018/07/learning-from-deaths-working-with-families.pdf>

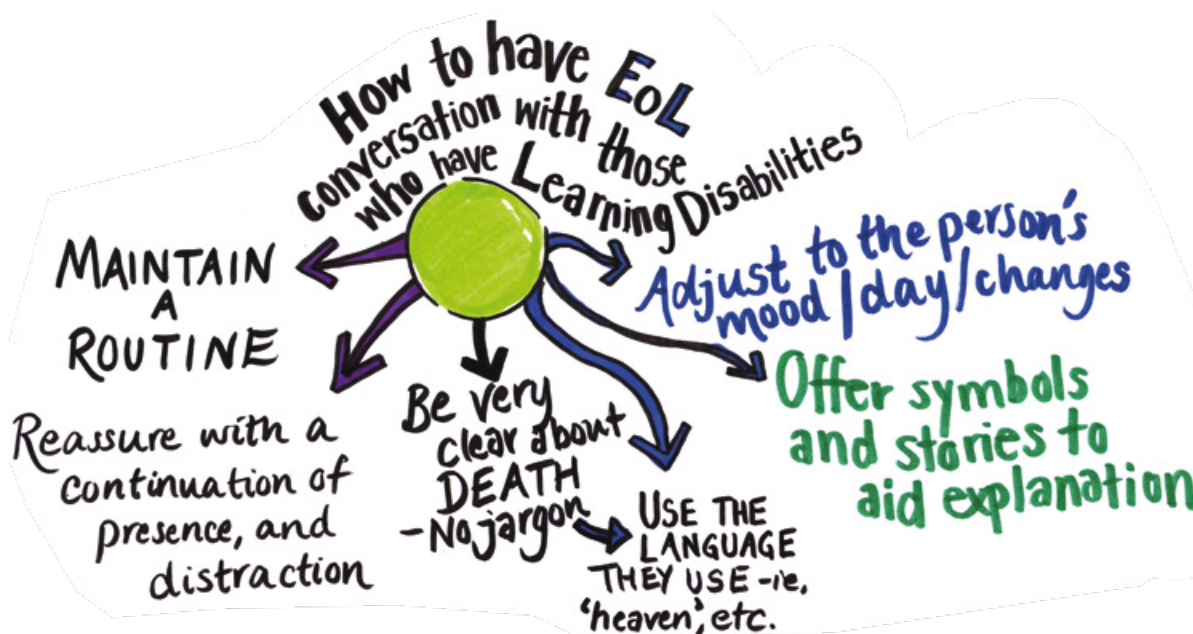


reduce dependency and increase independence. Staff and volunteers at the Hubs offer a range of therapies, specialist support and advice. Key messages were:

- Pre and post bereavement support is needed for families and friends to improve their understanding of what is happening and to help develop coping strategies during and post bereavement. Clinicians should initiate and feel confident to have conversations about preparing for EOL.
- There is huge support for the need to de-medicalise death within our society and to ensure better planning.
- EOL bereavement services are often provided by the voluntary sector who themselves may feel left 'out of the loop' and face financial difficulties.
- We need to identify and recognise specialist skills and services, encourage outreach and in-reach of hospice specialism and ensure clinicians are aware of the expert support they can access. The 24 hour advice line for professionals was acknowledged and a similar 24 hour helpline for families could be considered.
- Value partnership working with other non-health and social care sectors for ideas and solutions i.e. to reduce duplication and time wasting seen in the current system.
- There was recognition that asking people to support those at EOL is a huge ask. Services need to be well publicised and easily found for ease of signposting, with new ideas for groups and community hubs, pubs etc.

## 5. Daniella McConnachie and Rachel Brown, Spectrum

### Learning Disability (LD) Approach to EOL Care





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The Spectrum team focused their discussion on how to have ‘the’ conversation with people who have a learning disability. Key concepts included:

- Use person-centred care plans taking into account people’s likes and dislikes.
- Talk about death using appropriate, factual language and support people to attend funerals if they want. Use social stories, interactive and engaging tools such as tablets and resources available to people with LD or autism.
- Consider a role for Acute Liaison Nurses at RCHT for EOL/with EOL competencies at all times.
- Explain and include the Mental Capacity Act when working with families and work with people who know the person well.
- People with LD may need on-going support when bereaved.

“Raise awareness of communication styles when supporting Patients/relatives with Learning Disabilities”

## 6. Jody Wilson, Healthwatch Cornwall, Case Study

### Mr Vale’s EOL Care

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HC colleague Jody Wilson facilitated the session to understand how we can collectively improve EOL in Cornwall, where ‘Maggie and John’s Story’ provided the platform for discussion as a real life experience. In summary, suggestions included:

- Empower staff to challenge decisions and not make assumptions - a culture change from ‘doctor knows best’.
- Improve communication between staff, patients and family, with more contact and updates - check people’s understanding.
- Better training is required for all staff to provide support with all aspects of communication and bereavement - psychological and not just medical.
- There is a potential role for a coordinator or navigator to support the patient and family and ensure better service coordination.





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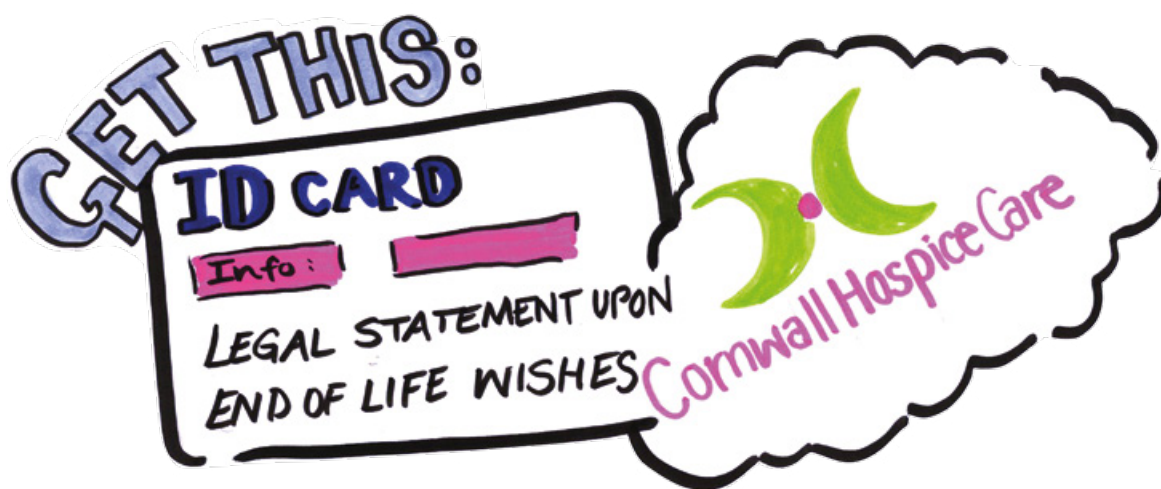
## 7. Debbie Thomas, Cornwall Hospice Care

### Understanding and Creating Advanced Decision Plans

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Introducing Healthwatch and Cornwall Hospice Advance Decision Cards, and starting the conversation on EOL wishes. Key concepts for introducing and encouraging the use of the Advance Decision Card and plans were as follows:

- Use the Advance Decision Plan as a tool to start conversations about people's wishes and reduce assumptions.
- Encourage people to create a plan and understand the importance of one if you lose capacity - record treatment you do not want. The card is only useful in conjunction with the form.
- Tell people you have a plan, including your GP, and where it can be found. Talk through decisions with family and friends and add their names to the document. Get it witnessed by someone (this can be anyone).
- Review it every couple of years to make sure it is current.



## 8. Jackie Horne and Deborah O'Nyons, Kernow CCG

### A Personalised Approach to EOL Care

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Introducing Personalised Health Budgets and challenges within Cornwall. This session examined when and how Personal Health Budgets can be fast tracked with EOL care needs, along with future aspirations for improvement to the service:

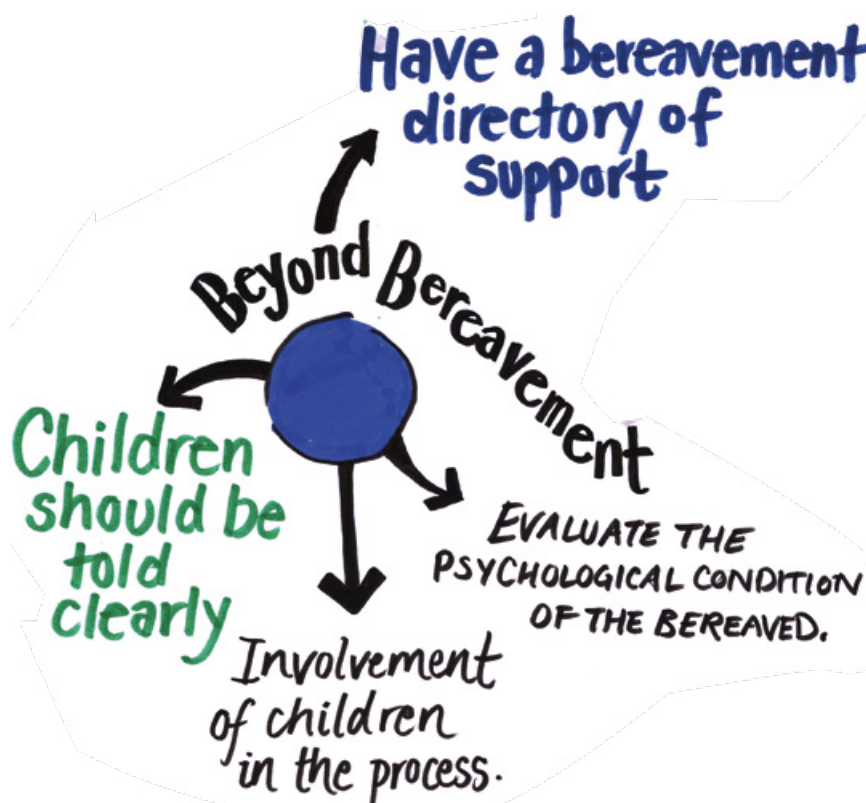
- The EOL register should initiate the discussion early - consider fast track options and what this looks like.



- Think 'outside the box' to offer a person-centred approach: help to improve peoples' understanding of treatment options and alternative therapies available to them.
- Culture is key: it's about what matters to the patient not the professional 'knowing what's best'. Pay attention to the silent minority who do not articulate their needs.
- Enable people to take responsibility for their own direct payments.
- Ensure people on the register have a plan when discharged from the hospice/ hospital.

## 9. Shelah Kester, Cruse Bereavement

Beyond Bereavement.



Alternative bereavement techniques and caring for the carer. Key points were:

- Establish a bereavement service directory to help people find support and/or a toolbox for signposting - paper as well as digital.
- Improve support for the carers of the bereaved.



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- Consider establishing support groups as a skills exchange, as per Age UK Beyond Bereavement [www.ageuk.org.uk/cornwall/our-services/beyond-bereavement](http://www.ageuk.org.uk/cornwall/our-services/beyond-bereavement)
  - Consider timing of support: at the time of death and thereafter.
  - Offer information on the different types of support and different options and techniques available and for different EOL scenarios such as such as suicide, terminal illness, learning disability etc.

## 10. Naomi Campbell, Reliance On Carer - ROC Hydration

### Introducing the Importance of Hydration in EoL Care

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Naomi Campbell explained how this unique, step-by-step framework to ensure patients receive adequate hydration, how it should be followed and what to expect:

- Encourage people to: be mindful of fluid intake and reasons for poor intake. Be aware of the risk of urine retention causing pain and agitation.
- Language and communication is key between healthcare professional's patients and carers.
- Currently, there is no validated, evidence-based tool to support hydration care in end of life. Health care workers and paramedics do not have a guideline or policy to support best practice as outlined by NICE (2015) Care of Dying Adults in last days of life . This results in unwarranted variation in care.
- We should consider tools that enable professionals, carers and family to continuously monitor and ensure patients remain hydrated.



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## To Finish

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### Two further quotes from our research:

“Death to me is peaceful. I know, and have discussed my end of life care and my funeral arrangements so that my partner is aware of my wishes. I would prefer to be kept at home for as long as possible surrounded by my own family, possessions and things that are familiar and comforting to me. I would only consider hospice care if I felt my family were struggling to cope with me being at home. I don’t want flowers at my funeral, I want a collection and money to be split between The Cats Protection League and The British Heart Foundation. I already have a will in place and have stipulated that. I know that end of life hospice carers are professional and caring but I would prefer my family to look after me with the help of outside means.

My husband has a power of attorney for me and after this survey I will discuss a living will with him as well. The part that scares me the most is the actual dying as it will be draining on my family and I don’t want to see them suffering. If I have to go I would wish it to be sudden so they aren’t put through all the pain of watching me die. Death itself doesn’t scare me, it’s the implications on my family that does.

“Quality End-of-life care should be a priority for the NHS”

# The End

(let’s ensure it’s a good one!)

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