



Catalyst Event Report on

Is there ever a right time to die?

***An opportunity to discuss, share and reflect on death and dying in the
context of the NHS***

Friends Meeting House, Liverpool, Friday 18th January 2019

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Is there ever a right time to die?

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Purpose

Setting the scene for this innovative and thought provoking day was a team from the Philosophy Department at the University of Liverpool, consisting of Dr Yiota Vassilopoulou, Dr Rachael Wiseman, and Professor Michael Hauskeller whose philosophical input invited new thinking around the subject of death and dying.

This event is part of the NHS R&D NW "*Philosopher-in-residence programme*" in collaboration with the University of Liverpool, exploring how philosophical input can influence our thinking and behaviour in the NHS and in particular on the end of life agenda.

The event brought together people from diverse backgrounds from across the North West of England who have an interest, either professionally or personally, in death and dying. It is hoped that the event enabled the attendees to begin to consider death and dying from a different perspective and to have conversations that will take their thinking in new directions.

This event was conducted using 'Open Space' ¹ technology and was designed to enable people with a mutual interest in death and dying to meet and progress ideas in a short period of time. Participants had control over what was discussed and could choose to include themselves in various conversations generated on the day. At the conclusion of the event, participants made decisions about how next steps to progress their conversations and were invited to contribute further through participating in the networks developed on the day and future workshops.

A summary of the Open Space discussions, including the names of participants and those expressing an interest in being contacted at a later date, form the basis of this workshop summary.

The discussions are not presented in any particular order and do not reflect the popularity or the merit of the conversation themes. Some themes are closely interlinked and could be collated.

An animated summary of the event was created on the day and can be seen [here](#). Also photos from the day are included in this report

¹ **Open Space** Technology. **Open Space** Technology (OST) is a **method** for organizing and running a meeting or multi-day conference, where participants have been invited in order to focus on a specific, important task or purpose. OST is a participant-driven process whose agenda is created by people attending.



Presentations

Professor Stuart Eglin, Chief Executive Officer for NHS Research and Development North West, introduced the event and explained how the “Philosopher-in-residence programme” was important to the NHS and the role philosophical reasoning can play in health care in general. Professor Eglin also explained the concept of the Catalyst event and how it was a highly participatory event. He stated that everybody attending the event had an interest in death and dying and all would have something to contribute. Professor Eglin then introduced Vajramudita Armstrong who was the facilitator for the day. Vajramudita showed a short animated film of [Open Space methodology](#) and then explained the Open Space process.



Embedding Philosophical Inquiry: Reflections on the Methodology and Outcomes of our Intervention.

Is there ever a right time to die? If we want to claim that there can *never* be a right time to die, we should be able to say *why* this is the case. That is not impossible. We may for instance argue that life itself is the highest good, so that nothing can be more important than to preserve a person's life for as long as possible no matter what the circumstances are, no matter whether that person's life is good or bad or indeed *how* bad it is. However, more is needed to make this claim credible. We should also be able to say *why* we think life is the highest good. Perhaps there are other things that are more important, more valuable.

Another option is to accept that *sometimes* it can be right for us to die. In that case the big question that we need to answer is *when* exactly and under *which* circumstances it is right for us to die. There are various possibilities we may want to consider. Perhaps the right time to die is when a person's suffering has reached a level that is no longer tolerable and there is no hope for improvement. Or, it comes when life is no longer experienced as meaningful for the one who lives it. Alternatively, we could focus more on the positive aspects of a life, in which case we may want to say that the right time to die is when we have had a full life and a fair share of the good that life has to offer. Or perhaps the right time to die is when we are in the right place and still lucid and well enough to enjoy it.

All these questions and many more that were raised during this *Catalyst* event point to the complexity of the issue and underline the need for all of us to have the space and time, as well as the appropriate framework to engage with it and learn from each other. But as much as this need may be felt, it is not often that we actually do talk about these questions because death generally is considered to be a taboo, a challenging and uncomfortable subject, even among healthcare professionals. A recent report by the Royal College of Physicians, *Talking About Dying: How to Talk About What Lies Ahead* (Bailey & Cogle 2018), highlights that healthcare professionals do not quite know how to talk about death with those in their care. They are unsure *how* to do it, *when* to do it, and *who* should be doing it, and for this reason often prefer not to talk about it at all.

These conversations are indeed difficult if they are to be meaningful and honest, that is, if they are to be more than a box ticking exercise.



In response to the RCP report, and as part of the *Thinking Matters* Philosopher-in-Residence programme, we aimed at offering participants the opportunity to hold these conversations, following an agenda consisting of questions that were introduced by participants themselves under this overarching theme. Our philosophical contribution to these conversations was not primarily an attempt to respond to these questions, but rather an attempt to motivate participants to focus on the questions themselves; to question the questions, as it were, prior to their own detailed attempts to offer responses. This is the first step in the process of philosophical inquiry, a step that we often tend to miss, perhaps being too eager to find an answer, to solve a problem, to make a decision—demands all too familiar in our everyday personal or professional life. However, the way we ask a question is almost always informed by our own perspective—a perspective that relates to our background, interests, values, preferences, aims and needs—not always evident, not even to the inquirer. For example, if we ask the question ‘*When* is the right time to die?’, we are strongly suggesting that there is indeed a time that would be right, even though such a commitment was not intended when the question was asked. It is also unclear what kind of response we are looking for when we ask that question: should it be an attempt to identify the conditions under which a given time is the right time (for example, when there is no possibility of recovery)? If so, a response such as ‘never’ is not likely to take us very far, unless the discussion shifts to a different question, requiring the examination of the reasons why there can never be conditions under which death would be considered the appropriate conclusion of one’s life. As one participant put it, referring to her attempt to initiate a conversation about death with her dying patient: “the questions you ask dictate the answers you get—or lack thereof”.

Philosophical reflection on the questions we ask ourselves and others, whether they are in our professional care or not, is not just a mental or academic exercise, as philosophy more generally is often misconceived to be: too abstract, too detached from ‘real life’. Rather, it helps us clarify our ideas, identify why a given question matters to us, what it is we want to find out, but also the assumptions, beliefs, prejudices or misunderstandings that may be informing our thinking, often unknowingly. Most importantly, this kind of critical reflection makes us face and deal with our own limitations and consider how open and prepared we really are to discuss a given question. In this sense, it is an essential part of our preparation or training, both as a society and as healthcare professionals, because it enables us to engage in a conversation in a meaningful and honest manner, which is particularly needed in discussions on such important matters as death. Empirical research, scientific data, expert opinions and other kinds of information are obviously very important but often insufficient to make sense of some of the most fundamental issues that determine our culture and attitude; if unquestioned, they are a serious impediment to change.



Yet it is precisely such change, as the RCP report confirms, that is needed if we are to talk effectively about death: “This is a challenging problem: it requires doctors, medical systems and societal attitudes to change” (p.12). Indeed, as is also highlighted by their feedback, participants really engaged in this process, and a change was already noticeable in the course of the event, in comments such as: “found myself walking away from here a bit less fearful of death itself”; or “thought provoking—the fact you can ask a question and there are so many questions as part of that question. As a commissioner of end-of-life services, it has been great to hear people’s different perspectives on things that I can take away to redesign end-of-life services here in Liverpool.”

As an illustration of how changes like this were brought about, the group discussing “how can we support people to die at home?” engaged in the process of critical reflection by considering ‘what is home?’ the fundamental question that had to be addressed in order to be able to properly respond to their chosen question. It became evident that the way we understand ‘home’ impacts directly on the meaning of the initial question. Does ‘home’ necessarily mean the place of one’s residence? What are the conditions for a place to be considered a home? In contrast to the recent past for example, it is very uncommon nowadays for one to be born, live and die in the same country, city, or neighbourhood, let alone the same house, and this has obvious bearings on our understanding of ‘home’. And what is it that matters most to one, *to be* at home or *to feel* at home? Depending on the circumstances, we may feel more at home in a place that is properly speaking not our home. Clearly, the way we understand home culturally or individually (and there may be a rift between the two) also affects the way we deal with the relevant practical aspects of the initial question. If ‘home’ means the place of residence, then the question concerns the ways in which those that are in their final stages of life will be able to spend them at that place rather than the hospital. However, if ‘home’ refers to a homely environment, a place where one feels safe, protected, in control, familiar, then the question would concern ways in which the hospital or hospice environments need to be designed and to function (both in physical and social terms) in order to provide this sense of being safe and in control. This is of course not a simple case of ‘either’/‘or’ but rather a contentious issue that requires the consideration of alternatives, diverse aims, multiple perspectives. Hence, the interrogation of questions, as the example shows, often leads to the second step of philosophical reflection, namely the clarification of concepts—the building blocks for our understanding and communication, which involves not only abstract thoughts, but also emotions, values, cultural traits and generally all these aspects that act as the foundations of our knowledge, character, actions, and interactions with others. It is by revisiting and revising them that we are open to change and in a position to effect it.



When a conversation like this reaches an end, it is usually not because it has reached a definitive conclusion. This is why, after the summaries of the conversations on a broad range of related but also distinct questions were communicated by the smaller groups' spokesperson to the whole group, we introduced the final step in the philosophical inquiry process. This consists in reflecting on the responses by focusing on some key issues, or patterns that could be identified as common elements in conversations that have already taken place. Unlike an ordinary summary, which aims at pulling together various threads to a tentative closure, this process helps bring to the fore all these aspects that were not actually discussed; the loose ends, the questions that we need to consider in more detail and depth, or the issues that we need to become more aware of, in future conversations.

There were three points in particular that emerged from the summaries of all the conversations that took place during the day, which we shared with the whole group at the end of the event.

1. **The importance of drawing or clarifying distinctions.**

For example, one question that was raised during a whole group session "Should we spend resources on the living or the dying and how do we decide?", seems at first to overlook the fact that since our birth we are all in the process of dying, without knowing for certain how far or how near death is for each one of us. Obviously such distinction between the 'living' and the 'dying' may rely on definitions like the one used by the General Medical Council (2010): we approach the end of life, i.e. death, when we are "likely to die within the next 12 months". Yet, would someone who has more than a year to live, but not necessarily much longer, be considered to be among the 'living' or the 'dying'? Small group conversations also highlighted that the very distinction between 'life' and 'death' is itself under question. Death may be understood as the opposite of life, but whether we accept that someone is dead and no longer alive when, for example, there has been cardiac arrest, or 'brain death' (and what the latter actually involves), remains contestable. So perhaps such a question creates a dichotomy between the 'living' and the 'dying' that may have implications or consequences (practical, ethical, political) we are not in a position to fully account for.



2. **The importance of becoming more aware of tensions or potential contradictions that our responses, practices, or policies may entail.**

There were two kinds of tensions that could be used as examples:

(a) The tension between the general and the particular case: “if life is different for everyone why isn’t death?” The ‘medicalisation’ of death, as noted by participants, is perhaps one of the reasons for the tendency to deal with death in a rigid manner, as if it were the same for all. But each person’s situation is in many ways similar (we are all human, we will all die, we all have rights, duties, wishes) but also in many ways different from someone else’s and as such, training, policies, and conversations related to death and dying need to be mindful of this. But how can training, policies and conversations that need to be effective and just for all, be flexible enough to meet the needs and respect the wishes of each individual?

(b) The tension between the professional and personal perspective of each individual carer: while professionals are expected to deal with a situation in a detached, ‘objective’ way, it is not clear what this involves and whether it is always the best course of action. It was particularly interesting to observe that even in those small group conversations that approached topics explicitly from a ‘healthcare professional perspective’, participants felt the need to contribute their own personal, subjective, experiences crossing, as it were, the kind of distance that their professional role often demands. Each individual’s different roles, that of the healthcare professional, the patient, the family member, may be at odds with each other, but it may very well be that ‘exploring the gaps’ more systematically and crossing the distance between them would be particularly beneficial. On the one hand, this may help develop more empathy between a carer and a patient; on the other, it may help support the carer to better deal with the responsibility, power, and limitations that their role as a carer involves. As one group put it, we “need to explore the gap between the individual, family, carer expectations and hopes and the ‘medical’ reality”. The comment was intended as an aim for palliative care to “close the gap”, but need not necessarily be confined to it. How do we strike a better balance between objectivity and empathy, professional and personal responsibility and integrity?



3. The importance of understanding what death means for the ones who are involved in a person's dying.

There seems to be a shared desire for meaningful conversations and meaningful moments when we are approaching death, and ultimately for a meaningful death, but it is far from clear what a meaningful death might actually consist in. Group conversations highlighted the fact that different individuals may have different needs at different times and that consequently not everything works for everyone in all situations. It also became clear that whether we are able to accept and even embrace death very much depends on the meaning we attach to it, as well as the meaning we attach to our lives. It is important what we believe death actually is, whether it is a part of our life or something alien to it and what, if anything, comes after death, what we believe life's purpose is, and what we think we have achieved in this life. Meaning, in other words, is always personal and transient: we find meaning in different things at different stages of our lives, and death, how we relate to our death and that of others, changes over the course of our lifetime. Some renewed understanding of our life's meaning may be required to become properly prepared for death and to be able to "let go". Sometimes meaning can be found in small things, "a friendly gesture or the kindness of a cup of tea offered by a stranger", or in experiencing a connection to others, be they friends or family, carers, pet animals or nature. Sometimes still, meaning can be found in the very process of coming to terms with our mortality, of being content with what we've had, of letting go, that is, both of our search for meaning and of life itself.



Clearly, those participating in the event appreciated the chance to “climb out of the normal structure and dip into some philosophical thinking”, as one participant tweeted during the event.

The provocations and challenges that such a climb-out entailed were widely experienced as enjoyable and indeed liberating, despite the sensitive, uncomfortable and rather depressing topic. It was good to have, for once, the space and time to talk about death and dying free from the usual constraints that we are subject to when we have to deal with it in a professional or personal context. Talking about death may still not be the easiest thing to do, but at least the event has brought us all closer to knowing how to do it and what questions we should be asking and trying to answer when we do it. Obviously, these questions are very real and the consequences of our responses tangible in our healthcare system and its future; yet the practice of philosophical inquiry, rather than a luxury or mere theoretical exercise is essential for reminding us of and preparing us for what is necessary for change. As remarked by participants, “I have been reminded how on-going clinical practice produces its own set of norms and way of operating and it’s been really refreshing, especially with the rigour that comes with proper organised philosophical thought, to be jilted out of that comfort zone.”

Yiota Vassilopoulou & Michael Hauskeller

University of Liverpool



Convenor reports

Convenor Name: Amy Gadoud

Topic of debate: How can we support people to die at home at end of life?

Participants: Sam Wright, Sam Clements, Becky Taylor, Caroline Pickstone, Debbie Wilde,

Key points from discussion:

- What is home – is it practical? Is it just 'not hospital', what is the support network?
- Impact on relatives and carers – ability to care 'expertise', long term legacy of death at home
- People haven't seen people die anymore – unaccustomed to death, unaware of 'messiness' or process. Unaware of extent of care needs
- Talk to our families about wishes around dying and funeral, organ donation
- Feedback to commissioners and stakeholders – NHS Liverpool

Next steps:

- Recommend the book 'With the end in mind' by Kathryn Manix, familiarize yourself with the process of dying and recommend it to others.
- Talk to hospices about engaging children – they can then talk to parents

Convenor Name: Graham Holland

Topic of debate: Role of faith in finding peace

Participants: Barbara, Graham, Jo

Key points from discussion:

- Spirituality vs faith
- Role of faith is different for everyone
- Different faiths have different beliefs and rituals around death and dying
- Required initial and repeated AX
- Offers community, belonging and support

Next steps:

- If faith is an important part of your life, it will be an important part of your death



Convenor Name: Gordon Southgate

Topic of debate: What is death?

Participants: Gordon Southgate, Josh, Bill, Sophie, Anna, Hannah

Key points from discussion:

- Separation, opposite of life, separation from life, cease to exist in this life
- Death can be welcomed or shocking, slow or fast
- Death is feared and not spoken about
- What is the purpose of death?
- Process of death is feared, the ones that are left behind, decay daily, can be used to manipulate / control
- Death is final, imminent to us all, it leaves those behind with grief / relief
- It can be embraced or avoided but rarely defined as its meaning can be subjective, however there are definites, we all die, there is either life after death or not.

Convenor Name: Many Tang

Topic of debate: 'Do not attempt to resuscitate' orders

Participants: David, Manu

Key points from discussion:

- More clarity / education around 'resuscitation' and public education, professionally
- Openness around death



Convenor Name: Michaela

Topic of debate: Assisted suicide

Participants: Ellie, Manu, Anita, Graham, Simon

Key points from discussion:



- Medicalisation of the dying process – ‘legalised assisted death’ whilst in a healthcare setting
- Withdrawal of medical intervention to facilitate a death – cases of MND
- ‘The right time to die’ withdrawal of medical intervention
- ‘Timing’ of a death – at the convenience of the family
- Duty of care – family / patient / staff – de brief and decisions
- Making the informed choice to die – should we not be supporting this
- Legalising assisted suicide – could lead to a slippery slope of ‘eradicating’ vulnerable
- The tension between prolonging life and ending life and the differing opinions around this
- Autonomy / capacity ‘forward planning’ for your death
- Impact on the pharmacist, nurse, GP on someone insisting they want to die

Next steps:

- ‘Watch and wait’ – what’s happening around the world

Convenor Name: Sin

Topic of debate: How should we decide to proceed with life extending / preserving treatment even if we know it may not work or may have diverse effects?

Participants: Christian, Susan, Anita, Helen, Jo, Manu

Key points from discussion:

- Do patients truly understand what the treatment involves, the risks and benefits?
- Patient directed goal conversations, when and how?
- The decision is the patients right? (cost driven??)
- Are we right to assume that life preserving treatment is good?
- Do we expect too much?
- Medicalisation of death – does society need to think whether this is the right thing?
- Intervention is perceived as being better than non – intervention (default position)
- Are we measuring the right thing? (in hospital deaths?) How do we measure a good death?
- Start planning earlier rather than later (its complicated!)



Convenor Name: Grace and Helen

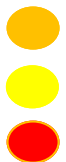
Topic of debate: How do we help the average person on the street to be comfortable talking about death?

Participants: Grace, Helen, Pippa, Sarah, Jayne, Mary, Kayleigh

Key points from discussion:



- Need to have conversations earlier – grave talk, church of England but not specifically religious
- Difficult to approach without a multi prolonged approach
- We've medicalised death so people are less comfortable with it
- Sometimes when you ask the question people are ready to have the conversation – often they are waiting for you to ask
- Dying is a process that start the day you are born – we should talk about it
- Is this a conversation that should be taking place in schools? Age appropriate conversations about death and dying? In PHSE lessons?
- We have birth plans – why no death plans? Should be an evolving document
- Talking about it is a huge responsibility, how so we help people deal with that responsibility? People need examples of what questions to ask?
- If you've worked it out yourself, its much easier to have the conversation with others



Convenor Name: Josh

Topic of debate: Is the topic of death important if one recognizes their immortality?

Participants: Gordon Southgate

Key points from discussion:

- Yes for morality (growing as a spiritual being) yes for judgment
- No if immortality is an extension of our own reality
- Depends of it you believe in life after death, if you do then it depends of if life's actions are consequential
- Belief / truth / authority is important to which the unknowing individual approaches actions in life / death

Convenor Name: June Eglin-Lowe

Topic of debate: How do we own our own death?

Participants: Sarah, Hannah, June, Ellie, Sophie, Carole, Jacqui

Key points from discussion:

- 'Why shouldn't it be me?' It always happens to the women next door, so why not me?
- Advanced directive, experience in death
- Discussing end of life decisions openly and using tools to do so
- Being familiar with our own death plan – meaningful engagement
- Awareness over death plan can change or unachievable
- Thinking outside of the box
- Contemplation, daily of our deaths

Next steps:

- More patient and family leaflets in hospitals
- More training for junior nurses
- More openness with consultants
- More chats with GP's



Convenor Name: Will Medd

Topic of debate: How do we enable people to answer 'the question' for themselves?

Participants: Simon, Robin, Will, Sam, Rosemary

Key points from discussion:

- Need to explore the gap between the individual / family / carers expectations (hopes) and the 'medical' reality. Palliative care aiming to close the gap
- Need to be able to create an environment / space where sensitive conversations can take place – at patients pace and continuous narrative over time (preferably)
- Power of attorney – could this be supported better? Decision making responsibility whilst feeling uninformed / disempowered need to be able to value the persons view point, whilst acting responsibly as a medical professional
- Balance between medical objectively / expertise whilst not disempowering people, leave them questioning 'what might have been'
- Need to agree roles / expectations – a 'contracting' process to explore peoples experiences / views / hopes
- What does the person want? Empower without making carers feel responsible for situations. Being alongside them to look at the situation together, rather than try to problem solve as an 'expert'
- People may need to know about the process of dying / loss of facilities / Especially people with power of attorney. The potential end of life trajectory for the person, if not now...



Convenor Name: Martin

Topic of debate: What would we like to die of?

Participants: Grace

Key points from discussion:

- Pneumonia?
- Quicker is better
- Not painful
- 3 months might be good
- Assisted suicide isn't such a bad thing – see Oregon experience – in control of the process

Convenor Name: Hannah

Topic of debate: Is the right time to die due to the individual or collective?

Participants: Hannah, Jayne, Carol

Key points from discussion:

- Injustice if they 'don't get a full life'
- Prolonging peoples lives
- Is there a criteria for life?
- If 'life' different for everyone why isn't death?
- What are the essential things to live?
- A meaningful life is different for everyone – what makes the want to die?
- Lack of purpose



Convenor Name: David Scott

Topic of debate: End-of-life care

Participants: Alex, David, Barbara

Key points from discussion:

- Its personal
- Issues to do with staff training
- Importance of music



Convenor Name: Rosemary

Topic of debate: Is modern medicine doing too much?

Participants: None recorded

Key points from discussion:

- It is about giving patients a choice, more control on treatment options?
- Is it dependent on patients overall quality of life?
- Right to refuse but not a right to demand treatment
- Modern medicine can do amazing things but needs to be a balance



Convenor Name: Sarah

Topic of debate: What is a good death? How do we enable people to accomplish this?

Participants: Kayleigh, Debbie, Michaela, Ellie, Sam, Sarah, Caroline, Mary, Grace

Key points from discussion:

- Bad death leaves a nasty memory for the people left behind
- Good death - being involved in decisions around where, pain free and environment
- Different components for patient, family, healthcare staff
- Taboo about dying alone – presumption
- Family to be there at the very end
- Socially constructed
- What empowers people to have a good death?
- Death needs to be within persons control
- Access to having an 'advanced directive' (living will)
- Frayed relationships needing to make amends
- Individualized death is a good death need to have control
- Giving information to relatives on what to expect at point of death (death rattle)

Next steps:

- Having a death plan is an important part of future plans



Convenor Name: Martin, Carole and Christian

Topic of debate: How do we measure a good death? How do we help medical professionals not to view death as a failure?

Participants: Stephen, Robin, Sin

Key points from discussion:

- Chemo or no chemo for stage 4 cancer (lung and bowel) when benefits limited
- Who has conversations re effectiveness of treatment, are they really honest? Just because we can treat it doesn't mean its right to do so
- ACP who should initiate conversation?
- Communication 'nothing we can do'
- Futility and treatment very honest
- Our culture doesn't facilitate EOL issues and discussions
- Need to create the environment to help make conversations easier
- EOL and DNAR should become part of normal healthcare conversations
- Health economies – cost effectiveness of hospital care vs care at home
- Common understanding between patient and medics



Convenor Name: Georgina Asgaard

Topic of debate: How can we create meaningful moments for the dying and who can do it?

Participants: Susan, June, Michael, Norraine

Key points from discussion:

- Meaningful moments = beautiful moments (sense of hope)
- Are meaningful moments simply happy moments?
- Meaningful impact through talk about a persons fear of death with them
- Is it better for an outsider to provide that consultation?
- Meaningful moments come from 'making a connection' when you open yourself up, giving peace and creating comfort for patient and family, sometimes by providing a cup of tea
- Protocol / plan in place but does not provide meaning: sometimes else needs to be brought in – a musician, a pet etc.
- Different individual's may have different needs at different times, and not everything works for everyone, you have got to 'tune in'
- Care and love are important even from people you don't know. Sometimes a touch of a cup of tea can make all the difference ' the smallest act of kindness'
- Everything you do is meaningful for the patient and their family
- Important also to break the loneliness and emphasize togetherness
- Acceptance and letting go



Convenor Name: Will Medd

Topic of debate: Who dies? What are they letting go of?

Participants: Jacqui, Stuart, Sarah

Key points from discussion:

- Challenging and letting go of the life you've lead, the people you're leaving – willingness to do that
- Buddhist perspectives as preparing to die, preparing for next life
- Being willing to 'accept' situation – enabling time to prepare and for family and friends to prepare
- Now we live life in a way that prepares us to let go, the meaning you give it.
- If you find you've lived life well, given it meaning it is easier to let go?
- Hard if 'angst' about what you haven't and haven't done
- What happens if more into 'awareness' of who we think we are
- Often try to help people maintain / hold together identity, rather than helping them let go?
- 'Who dies?' raises many questions about what people try and grasp at the end of life
- How we live our life can be a powerful preparation for how we die – for example what we identify with, what we let go of, what we accept and who we think we are.

Convenor Name: Alex Douglas

Topic of debate: How do we care for, understand the rights of, and advocate on behalf of the patients with intellectual disabilities facing end of life?

Participants: Amy, Norraine, Jo, Martin

Key points from discussion:

- Patients with intellectual disabilities are going to die, why does our training not prepare mental health and nurses for palliative care?
- All clinical trainees should work in palliative care



Convenor Name: Helen

Topic of debate: Is it discrimination to treat death differently in elderly or disabled people?

Participants: Jacqui, Anita, Sarah, Carole

Key points from discussion:

- Yes it is discriminatory to treat death differently in the elderly or disable
- Acknowledge that discrimination exists and when there will be hidden and obvious blame



Summary of the day

This summary is for the purposes outlined at the outset and records the conversations held on the day serves as a reminder of discussions for those individuals involved or those who have since expressed an interest to be kept informed.

Everyone who attended the event and any one who reads this report is invited to continue the conversation around death and dying. Future workshops on this topic will be shared with participants and anyone who requires further help and support to progress their ideas on this subject should contact NHS R&D NW.

NHS R&D NW would like to thank everyone who took the time to join the conversation on death and dying and to our philosophers-in-residence for their unique contribution on the day.



Changes in thinking and practice

- *I found it interesting to see how there were so many different topics and different conversations, but there is also some overlap and it is something instinctively human how we all go for the same answers and we all want to answer each question.*
- *Chance to get the views and opinions from a wide variety of people's backgrounds.*
- *Training issues all around. Perhaps we could have special sessions in the training of doctors with people who have had the death experience.*
- *Different perspectives on death.*
- *I found it very interesting and found myself walking away from here a bit less fearful of death itself.*
- *Very interesting and intimidating to be in the presence of so many professionals in this difficult area and a unique experience to hear people talk about death and different problems that they have, as it were, outside of that context. On other occasions I have met them as doctors and as advisers but now they are talking about the difficulties they have on those roles.*
- *Thought-provoking the fact you can ask a question and there are so many questions as part of that question and as a commissioner of end-of-life services, it has been great to hear people's different perspectives on things that I can take away in to redesign end of life services here in Liverpool.*
- *It's the perfect set up and I guess my biggest follow-up questions are how can our social systems and networks help us to answer these questions to continue that and how does that impact social services?*
- *A very good mix of opinions and viewpoints, which I greatly appreciated and also I would like to hear more from the philosophers in terms of the intellectual rigour with which I can develop my own philosophical investigations.*
- *I think it's been reassuring to find that lots of other professionals have the same difficulties that we, in our team have but encouraging some of the things that we are doing in our Trust are probably very positive.*
- *I think what I am taking away today is probably that we need to talk on all levels and consider the philosophical elements but also the practical elements of how live and die well.*
- *I found the initial spectrum of questions really very fascinating in that they were so diverse and I think led us to a set of sessions that really captured that balance between conceptual exploration and personal experiences.*
- *It's just as important dying as it is in living and being born.*
- *...Which is why it matters that we talk about death much more than we do . We need cross-cultural conversations, interdisciplinary conversations, that actually enable more people to experience death better than is the case right now.*
- *Especially helpful the philosophical reflections and in particular how we can ask questions and that actually asking questions can be much more helpful than more answers.*
- *I found it really interesting and thought provoking day over all. I appreciate that there was a willingness to just ask more questions.*
- *I found it interesting that there is such a wide range of jobs and skillsets here and how personal opinions overlapped but matched as well; it doesn't matter what are jobs are, our opinions can be so similar.*
- *I think it's been really good to talk as much about death as about life and it's been really thought provoking.*
- *Really refreshing to talk about such an important but difficult topic in such an open and very diverse way.*
- *I've just enjoyed how we have been able to all talk about death with very different backgrounds and professions none of us is an expert on death, but we will all get there one way.*

Changes in thinking and practice

- *I think for me it was about the discussion we've had about the life course and needing to ensure that at every stage of the life course we talk about death and dying. From young kids at school we need to change the culture and build a context where it's just normal to talk about death and dying.*
- *I've derived a little hope from today from seeing so many thoughtful, intelligent, emotionally aware people that are putting a lot of thought into this, which I have previously felt quite disheartened that the elephant in the room is never spoken about really.*
- *I am feeling grateful for being here today and I'd like to thank everybody for sharing their stories and I found it challenging, so thank you everybody.*
- *It's been great; wish it could last for a week this. Because you feel you're just touching the surface of the whole conversations. There've been some great questions and topics brought up, and more questions. It's been really good.*
- *It highlighted the extent to which we do not talk about death both personally and as a society. Thank you really to everybody for creating such a safe and supportive space to be able to talk about such a sensitive topic really respectfully done in our group.*
- *As a philosophy student, I really enjoyed hearing the philosophers talk but also hearing opinions from healthcare professionals that I never would have normally got to speak to, so thank you very much.*
- *I really enjoyed the very mixed audience and different points of view and I think we need to find some way of building all this stuff into the way the health service is managed which may be hard.*
- *I've been reminded how on-going clinical practice produces its own set of norms and ways of operating and it's been really refreshing, especially with the rigour that comes with proper organised philosophical thought to be jilted out of that comfort zone.*
- *I do feel inspired by listening to the summaries to both talk to my parents about death and also contemplate it more for myself, and what that means for living.*
- *We acknowledged that death can be a taboo subject, so it's just brilliant to see and hear so many here today being prepared to talk about it and the philosophical inquiry elements I think hopefully have nudged a lot of us in our thinking and I am hopeful that we can go away and start our own conversations about death and continue to make death less of a taboo.*
- *Today has just affirmed that thinking really does matter, it's not just about the results or the answers we get. Sometimes we focus on what is the answer to this, but it is important to spend time to develop our ideas and listen to others rather than think just about the end result.*

Tweets from the event

Sarah Price @SarahPrice101 · 3d
 @NHSNWRD @thestuarteplin Great day in Liverpool today. Thought provoking stuff; some of that thinking will stay with me for a long time. Refreshing to climb out of the normal structures and dip into some philosophical thinking. Thank you! #ThinkingMatters

🗨️ 2 ❤️ 4 ↗️

David Garbutt @David_Gar... · 3d
 Fascinating day talking about the nature of death #thinkingmatters

🗨️ 1 ❤️ 1 ↗️

Simon Edgecombe @Edge... · 3d
 A morning spent
 Immersed with strangers
 In the stuff of death
 And autonomy
 -
 I use mine to step outside
 Inhale the street murmur,
 the January sleet
 a stale pub kitchen
 -
 Keen alive
 #thinkingmatters

🗨️ 1 ↗️ 1 ❤️ 4 ↗️

Simon Edgecombe @Edge... · 3d
 We surround ourselves with like minded opinion. SO good to have that challenged! Thanks to R&D NW and Liverpool Uni for a great structure for some great conversations. #thinkingmatters

🗨️ 2 ❤️ 4 ↗️

Kayleigh price @kayleighp... · 3d
 Had a great day today at #thinkingmatters in Liverpool talking about 'is there a right time to die'. Nowhere near as depressing as it sounds- felt energised talking openly about death, and the social constructs we build around a 'good death'. #foodforthought

🗨️ 2 ↗️

Sarah Dyas @Dyas3Sarah · 3d
 Visual animation from #thinkingmatters day on 'Is there a right time to die'

🗨️ 1 ❤️ 2 ↗️

Martin Rathfelder @rathfe... · 3d
 Medicine can do a lot these days but it cant stop us dying and there comes a point when its better to stop trying #thinkingmatters

🗨️ 1 ↗️

Amy Gadoud @agadoud · 3d
 #thinkingmatters recommending @lanDewar @drkathrynmannix talking about raising public awareness of dying @IOELC

🗨️ 2 ❤️ ↗️

Postcard Feedback

Very enjoyable day in a comfortable environment

A very thought provoking day which I will take with me into my clinical practice

I really enjoyed the philosophy input

Good to hear other views and perspectives, open space event was a very good experience

A fascinating set of topics and discussions

Enjoyed the [Open Space](#) concept and a great venue

This has been an excellent stimulating opportunity to discuss perhaps the most important topic of all of our lives with a great mix of people from different professional backgrounds

The thinking matters event was an unusual and informative agenda. The style of the day was unique and definitely a change up from the usual style of meeting

Excellent thought provoking day – really appreciated the mix of different backgrounds and open discussion format

Philosophical insights provided helpful summaries

