

## »The dying person is an endangered species«

An Interview with Allan Kellehear

## »Der sterbende Mensch ist eine bedrohte Art«

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Ekkehard Coenen und Miriam Sitter

In the interview series of the *Annual Review of Death and Society*, conversations are held with well-known personalities who have researched topics such as dying, death and bereavement in a sustained manner and have published highly relevant books, chapters and articles of outstanding importance for the thanatological community. The initial interview was conducted with Allan Kellehear on January 27, 2022. Kellehear is a medical and public health sociologist specialising in death, dying, and end-of-life care research. He holds a PhD in Sociology from the University of New South Wales in Sydney (Australia) and is a Fellow of the Academy of Social Sciences. Much of his work is devoted to end-of-life behaviour in palliative care, critical care and elderly care. Furthermore, he has done significant historical, sociological and socio-psychological research on the experience of dying. He has also created public health models for the care of the dying, bereaved and caregivers. In addition to chairs at the Universities of Bath, Bradford, and Middlesex (England), he has held a chair in palliative medicine at La Trobe University in Melbourne (Australia) and the annual chair of Australian Studies at the University of Tokyo. Furthermore, Kellehear has held numerous guest or honorary professorships in Australia, Austria, Canada, Hong Kong, Ireland, the United Kingdom, and the USA, and a Distinguished Lectureship at the Clinton Presidential Library in Arkansas. In conversation with Ekkehard Coenen and Miriam Sitter, Allan Kellehear talks about his career as a thanatosociologist, the challenges in sociological research on dying, his critical attitude towards psychological and sociological studies, current attitudes towards dying, compassionate communities, and dying during the Covid-19 pandemic.

*Thanato sociology, dying, sociology of dying, psychology of dying, Covid-19 pandemic*

In der Interviewreihe des *Jahrbuchs für Tod und Gesellschaft* werden Gespräche mit namhaften Persönlichkeiten geführt, die nachhaltig zu Themen wie Sterben, Tod und Trauer geforscht und Publikationen veröffentlicht haben, die in der thanatologischen Community von herausragender Bedeutung sind. Das erste Interview dieser Reihe wurde am 27. Januar 2022 mit Allan Kellehear geführt. Kellehear ist Medizin- und Gesundheitssoziologe, der sich auf die Erforschung von Tod, Sterben und Pflege am Lebensende spezialisiert hat. Er promovierte in Soziologie an der University of New South Wales in Sydney (Australien) und

ist Fellow der Academy of Social Sciences. Ein Großteil seiner Arbeiten widmet sich dem Verhalten am Lebensende in der Palliativ-, Intensiv- und Altenpflege. Er hat darüber hinaus bedeutende historische, soziologische und sozialpsychologische Forschungen zur Erfahrung des Sterbens durchgeführt. Zudem hat er Public-Health-Modelle für die Betreuung von Sterbenden, Hinterbliebenen und Pflegekräften entwickelt. Neben Lehrstühlen an den Universitäten Bath, Bradford und Middlesex (England) hatte er einen Lehrstuhl für Palliativmedizin an der La Trobe University in Melbourne (Australien) sowie den Annual Chair of Australian Studies an der University of Tokyo inne. Darüber hinaus bekleidete Kellehear zahlreiche Gast- oder Honorarprofessuren in Australien, Österreich, Kanada, Hongkong, Irland, Großbritannien und den USA sowie eine Distinguished Lectureship an der Clinton Presidential Library in Arkansas. Im Gespräch mit Ekkehard Coenen und Miriam Sitter spricht Kellehear über seinen Werdegang als Thanatosoziologe, die Herausforderungen in der soziologischen Sterbeforschung, seine kritische Haltung gegenüber psychologischen und soziologischen Studien, über aktuelle Einstellungen zum Sterben, mitfühlende Gemeinschaften und das Sterben während der Covid-19-Pandemie.

*Thanatosoziologie, Sterben, Soziologie des Sterbens, Psychologie des Sterbens, Covid-19-Pandemie*

**Miriam Sitter:** As you already know, Ekkehard and I are a part of a thanato(socio)logical working group that deals with the topic of dying, death, and bereavement.<sup>1</sup> And within these topics, it is, of course, always about dealing with certain taboos and also about normative pressure, inattentiveness and moments in which sensitivity and a bit of self-understanding have to be discussed. We know you have worked in many different places around the world, teaching and researching on different subjects, particularly the experience of dying and palliative and end-of-life care. An area in which the mentioned topics like taboos and sensitivity, I guess, can also take place. And you have also held various professorships in this context and published numerous books and articles. But, of course, you first started studying and doing a doctorate in sociology before you took on these later tasks and topics. So, how would you describe your path to your expertise on specific issues related to dying and end-of-life care?

**Allan Kellehear:** First of all, I was an undergraduate in Australia, a sociology student, and at that time, it was the 1970s. There was a group of academics at my university interested in the relationship between sex, death, and madness – those three things. And I fell under the influence of a couple of them who were interested in psychedelic anthropology – this is anthropology inspired by LSD and other forms of altered states of consciousness. So, there were people like

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1 We thank Jörg Schoolmann for his support in preparing this interview transcript.

Alan Watts (1965), who was a theologian and anthropologist, there was Timothy Leary (and colleagues) (1964), who was a psychologist, and Allan D. Coult (1977), who was a really interesting anthropologist in academic terms alone. For instance, he'd only ever published one book, but his followers mainly read his unpublished works, which were circulated internationally as unpublished copies. And I was lucky enough to get a set of photocopies of his unpublished works.

And I studied Alan D. Coult's work, as well. That led me to an interest in anthropology. I had a long history of studying death and madness in particular. I actually specialised in anthropology in my sociology degree. In the final part of my course, we had to do a dissertation, and I chose two anthropologists to guide my dissertation and be supervised by them. And then I went to medical school, which I hated. I did that for two years. But while I was there, I developed a friendship with the professor of psychiatry. That was a woman called Beverly Raphael. She had spent her entire career studying bereavement. Beverly wrote two very famous books published by Basic Books in New York, one called *The Anatomy of Bereavement* (1983) and the other one called *When Disaster Strikes. Looking at Death and Dying in Grief and Disaster Context* (1986). Anyway, Beverly and I became very good friends, and when I decided to do my PhD (1982–1985), I asked her if she would co-supervise it with a sociologist. So, I did my PhD with Beverly, because at that time in Australia, there was nobody interested in the sociology of death and dying. So, Beverly had spent a career in bereavement, and I thought she knew the broad literature quite well. And eventually, I decided to do my PhD study, a cross-sectional interview-based study of over 100 people with less than six months to live. So, I studied dying. I chose the experience of dying to do my dissertation on. And that's how I got into it, as an undergraduate, and then later as a postgraduate. What I discovered was that I was not interested in anything else. So, I stayed, studying dying – and later its care – for my entire career. Also because of a quirk in my career, I began developing and writing about public health models for its care. So, when I was offered my first professorship in Australia, it was a palliative care chair. But I never liked palliative care. I always distrusted it.

**Sitter:** Why?

**Kellehear:** Up till then, palliative care was largely a very medical enterprise. It was obsessed with two things: It was obsessed with symptom management (or symptom science), and health services research. And I know many colleagues in psychology and sociology who went into palliative care and basically did health services research, which to me meant they weren't developing palliative

care at all, they were just providing evaluations for the current service arrangements. I considered this drone work. So, for me to be in palliative care, I would have to develop a social model. At the time, when I went into palliative care, there was no social model. There was a ›psychosocial‹ model. And as I'm always fond of saying: The problem with the psychosocial model in palliative care is that it's always more psycho than social. So, I developed a social model, but I needed to develop a social model that clinicians could understand. And that's why I decided to develop a public health model, which is essentially a health promotion model, and the compassionate communities/cities ideas that I would later become known for all emerged out of that. That was the only way I felt I could work in palliative care. I could only work in palliative care on my own terms. But it meant that I was the only one when I first came to this very clinically-oriented field. So, I had to sell the idea of a social model of palliative care as a public health model.

**Sitter:** It's a long and quite personal history.

**Kellehear:** Yes, it is – a peculiar history. I was just a lecturer in sociology. For the first ten years, I just had normal appointments in sociology. And a lot of my senior colleagues said that the study of dying would be a career killer.

**Sitter:** A ›career killer‹ – I have a faint idea what that means. But what exactly is behind it?

**Kellehear:** The phrase ›career killer‹ meant that I would never get a professorship if I kept up with studying dying. I would never get a promotion. Many said I was lucky to have a job. People said these types of things and many other disparaging things to me at the beginning of my career, but the problem for me was that's all I was interested in. I didn't know what else to say or do. So, after my dying of cancer thing, I studied near-death experiences, which was even worse from the perspective of my onlooking colleagues! People thought I had lost my mind when I started studying near-death experiences. But I was just doing sociology, and I was just doing that study of the near-death experience combined with some anthropological perspectives, I was also doing some political economy work. I was doing some sociology of knowledge work. I wasn't doing parapsychology. I wasn't doing religious studies. I hadn't turned into some kind of New Age writer. I was simply doing sociology. I just happened to choose a very interesting, if esoteric, aspect of the dying experience. But some of my detractors started to worry me in those early days. So, I decided to change that a bit. Every time I published one book on dying, I published two more on something else to help my career. I published *Dying of Cancer* (1990a).

Then I published *Every Student's Guide to Sociology* (1990b), which was an introductory sociology book. And then I published *The Unobtrusive Researcher* (1993) which was a research methods book. I ended up publishing four research methods books (1993, with Colquhoun in 1993, 1996, with Daly and Gliksman in 1997) and two introductory sociology books (1990b, 1996), when I'd only published two books on dying. So, in Australia, I ended up becoming quite well known for my research methods books. But when I finally got my first chair in palliative care in Australia I stopped all of that. And I decided I don't need to pretend to be interested in anything else. So, I just stopped, and I only continued to write books on dying or its care. That's what I've been doing for the last, I don't know, 20 years.

**Sitter:** You've mentioned some theoretical thinkers like Alan Watts and Alan D. Coult. Are there any more theoretical thinkers that shaped your view and your thoughts?

**Kellehear:** The psychedelic anthropologists only influenced me to move into the topic of death and dying. Once I got into death and dying, I would have to say they weren't particular thinkers that were influential in a singular way. On the other hand, my work has largely been a conversation. My studies of dying in particular, have been a critical conversation with psychology. I have been a heavy critic of psychological studies of death and dying.

**Sitter:** To what extent? Could you describe this a little more?

**Kellehear:** I was critical of psychology well before most sociologists were critical of medicine and medicalisation. And by that, I mean to include psychoanalysis, behavioural psychology, and psychiatry. I have been constantly engaged in providing alternative views to what some people call the 'psychiatric deluge'. This idea of people's experiences at the end of life is best understood through the solely emotional and cognitive experiences, their psychology if you like, separate from the social structures and influences that create and support them. Sigmund Freud has been troublesome to me for a very long time. And I have absolutely no time for Anna Freud. And, of course, there is Ernest Becker (1973). Now, I know Ernest Becker is technically an anthropologist, but I consider that Becker to have sold out, epistemologically speaking, as someone who has betrayed his epistemology. He does not write like an anthropologist. He writes like an apologist for the Neo-Freudians – promoting the idea of the denial of death, and of death-denying societies, despite abundant cultural evidence to the contrary. And the recent incarnation is the 'terror management'

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people pushing the same line but often promoting psychometrics scales and surveys to prove their point.

**Sitter:** What do you mean?

**Kellehear:** So, psychologists have been very influential in the field of death and dying. But my critical position of these perspectives has pushed me deeper into a sociological epistemology. And I've had to therefore engage with Philip Ariès (1974, 1981), and people like that in exactly the same way. Ariès is essentially a historian of the middle classes. He talks about dying as if the Middle Ages was emblematic of human death and dying. And that's just not the case. Forget about the criticisms of the underlying Catholicism of his data. But the fact is that his idea of dying is not generalisable to the peasantry, or the working classes. And it's also very time-limited, in the sense that it's very agrarian society-based. It's based on an idea of dying which was popular in agricultural societies. In the end, I became a critic of Ariès as well, because Ariès, like Ernest Becker, seems to ignore the cross-cultural data. And this is a problem when you are too immersed in your own epistemology. And that's why in the end, I've gradually become increasingly interdisciplinary in my work. So, if you look at my *Social History of Dying* (Kellehear 2007) for example, I draw on archaeology, demography and epidemiology, and religious studies. I tried to have a loose hold on my own sociological epistemology whilst driving forward with that as the central direction. It's the same with *The Inner Life of the Dying Person* (Kellehear 2014). Some people say that's a psychology book. It's not a psychology book. It's a social psychology book. If I'm a psychologist then Erving Goffman (1959) is a psychologist in the same sense; but if we are ›psychologists‹ we are so only in the sense of showing how thinking and feeling and responding are deeply embedded in circumstance and context. Real psychology cannot be understood separate from its context and Goffman's argument was the same. So, in that sense, social psychology is a sociological psychology. And it's not the same as a behavioural sciences perspective on our need to be understood entirely as individual responses, shall we say. So, my conversation has largely been critical, but at the same time, it's been a sort of collaborative, revisionist dance with the psychologists. However, and at the same time, I've gradually become critical of sociologists.

**Sitter:** Why have you also been critical of the sociologists?

**Kellehear:** I've had trouble with some sociologists of death and dying although there have been some major exceptions, for example, Tony Walter (1994, 2020), and people like that. But many other sociologists believe that to study

dying you have to follow doctors into their offices. And that's a mistake. It's a big mistake because dying happens everywhere. And it's also much longer than the little bits and pieces you see in the hospital wards, the hospices, or the nursing homes. So, the widespread idea is that if one studies dying, you just do what I did when I was a student, go to an oncology ward, and interviewed people there! When you do this kind of thing you think you're studying dying. And you are, but you are only studying a very, very small bit of the dying experience, and maybe not the most important part. And also, if you keep studying dying from one cause, for example illness dying, you bias and distort the human confrontation with death by generalising from one type and within that one type over-emphasising the last days only. So once again, I have problems with the sociological field of death and dying when it obsesses over dying in clinical settings alone.

We have been overly influenced by psychologists, overly influenced by sociologists who, like Glaser and Strauss (1965, 1968), think that dying is only about studying illnesses. And so, we ignore all the studies that we have in military history, or from death camps, or death row, or disasters, or any other sort of circumstances such as suicide, homicide, or simply ageing. We too often uncritically embrace the idea of dying as a physical journey, like Sherwin Nuland's (1993) idea of death as physical collapse. And I completely reject this idea of the physicality of the dying experience. People can be biologically dying but feel that they're quite healthy, and they're not dying people at all. And people who are absolutely healthy will kill themselves in four days, time or plan it as we speak, and their behaviour is almost identical to people who are dying of a terminal illness. Dying must be understood as a fundamental issue of identity. And that's the most important social sciences thing that we can say about dying, that it is an identity matter. Biology is perhaps necessary for its final definition, but it's not sufficient to define it as a human experience. These are very simple, sociological principles.

There is also a lot of white noise over the last 50 years of sociological to-ing and fro-ing in social science that conflates dying with death. The Americans often talk about death and dying like euphemisms for each other. They are not. Dying has little to do with death except as futurity. Dying is the last part of life. So, it's really a sociology of life. So, all of that stuff has been the kind of stuff I've been navigating for the last 25 years in a very critical manner. Being very critical of a psychological perspective, being very critical of conventional social sciences studies of dying that slavishly follows medicine into their clinics. I have tried to have a collective epistemological approach, or an interdisciplinary approach to the study of dying whilst still travelling in a firm sociological direction, believing fundamentally, in the sociological epistemology. But it has been important to understand that sociology is not enough alone and that a

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single epistemology in the matter of the study of the end of life can be misleading. You have to bring other epistemologies together.

**Ekkehard Coenen:** It's really interesting that you're so sceptical about some sociological work. And this leads directly, I think, to your introduction to *A Social History of Dying*. There you wrote that numerous authors on social theory would only speculate about death and dying without looking at empirical evidence. And you also noted that the texts are frequently turgid, sometimes esoteric, or often lethargic. How would you assess the relationship between the sociology of death, dying, and bereavement and the empirical effort today? Is it the same, or did it change?

**Kellehear:** I still think that first of all, the study of dying is not popular, even in sociology. And when people talk about dying, they will often talk about it more theoretically. And I think that's because it's easier to do that. The alternative is to do empirical work. I'm not overly a big fan of empirical work. But more importantly, what I am not a fan of is a blanket epistemological approach. So, I think that if you're serious about the study of dying, it shouldn't just be a matter of speculating. It shouldn't be a matter of just drawing on social theory alone. I think there's plenty of existing data from archaeology, plenty of data from anthropology, and plenty of data from epidemiology, and plenty of data from demography and gerontology, or from religious studies. We have fantastic case studies from military history, prison history, disaster studies, and also particularly from industrial, air, and sea accidents. And there's a wealth of empirical data there. Why would you need to speculate without recourse to looking at that wider existing set of data or case example? And then, more annoyingly, when my colleagues from social theory decide they want to take an interest in dying, they go immediately to the medical cases. And I find that not only paradoxical but rather ironic because it's uncritical. Why do you think the doctors have the secret source on life and death? Where does that come from? Well, on the one hand, we are critical of medicalisation. And then the very next minute, we're following them into their clinics as if we believe they have the only true access or glimpses of human mortality.

In many ways, things haven't changed that much. Every year, I get a PhD student who wants to go into a hospital and interview a dying person. And I say: Why do you want to do that? There's plenty of other data. So, to some extent, things haven't changed that much in the nearly 20 years since I wrote my social history. I think there are a lot of armchair theorists when it comes to death and dying because it's a safe place to be. I think interviewing somebody with a couple of days to live who's got a widespread metastatic cancer is a difficult thing to do. And I think that even studying descriptions of dying soldiers

on the First World War battlefield can be very, very upsetting. Even for an academic, it can sometimes be stomach-turning. If you read some of the cases of people dying, from colonial wars, scenes of dying Native Americans, for example from Dee Brown's *Bury My Heart at Wounded Knee* (1970), if you look at some of those descriptions, it's very, very difficult to read. And I understand that, and in some ways, you're better off emotionally speculating about your own mortality. And it's somehow more comfortable to do that, somewhat ironically. But if that's the way you feel then I don't understand why you would bother studying dying at all. It's easier to be a cultural studies person speculating about death than it is actually to confront the complicated details, both psychologically as well as the physical, social, and spiritual dimensions in the last hours of life. I think these considerations and sensitivities stop a lot of people from doing the actual experiential work.

**Coenen:** What we're particularly interested in is also your view on especially the Anglo-Saxon countries because we think there are quite a lot of differences between the sociology of death, dying, and bereavement, and in Germany, we call it thanato sociology. So, that's maybe the equivalent of the sociology of death, dying and bereavement. We are interested, how would you describe, for example, especially the history of the Anglo-Saxon countries such as England? We ask this primary because we have the impression that the considerations and the questions of the sociology of death, dying, and bereavement, enjoy some greater self-awareness and openness, for example, in England, than particularly in Germany. So, can you explain these tendencies?

**Kellehear:** I think if you're talking about the contemporary field, my observation has always been that if you move from West to East, if you go from North America to Britain, to Europe and Asia, you move in that direction, you can observe real differences in our field. As you move from left to right – as you move from North America to Asia – studies get increasingly theoretical. When you start in America, there's almost no theory. So, if you read the sociologists in America, sociologists of death and dying, they're almost atheoretical, they're extremely descriptive. They're very numerous. They like statistics. They like their demography. They like to describe issues, but they're not big on theory. Moving East we can say that the British like their theory, and they develop quite a bit of theory, but it's a very middle-range theory. So, it's linked quite carefully to an empirical phenomenon, to data. But data is limited. Most British colleagues would think about data that it is limited so interpretation is the most important part of any analysis – but the interpretive process must nevertheless be based on something substantial – interviews, surveys, historical records, or diaries for example. Then as you move into Western Europe, the grip on data

becomes increasingly less and less. And there is more debate about the theory for its own sake. And this is also the case in Asia, where discussions around death are very abstract rather than immersed in empirical data. And I think that in the more traditional societies, whether that's Japan or Germany, there are still traditional taboos, and traditional reticence even amongst the academics about walking into a hospital ward and interviewing somebody who is dying. But compounding that reticence is very often the cultural fact that ordinary Germans or Japanese are also reticent about the idea of speaking openly about these topics, and that's not quite the same in cultural terms for the Brits.

**Coenen:** Why?

**Kellehear:** The British are more open in public terms about talking about death and dying, and the Americans, well, you can't shut them up. They just love to talk about anything. I think there is a cultural difference as you move from North America to the UK to Western Europe, and then to Eastern Europe and Asia – this move tracks the increasing cultural reticence, decreasing expressivity, and social ambiguity. This reflects how the traditional political and cultural structures in the respective societies (from West to East) still hold a grip on popular and public thinking and acting. That's just how I observe it.

If we were just sitting around having a cup of coffee, Ekkehard, I would say to you, the Americans are not theorists at all, but they're very original. They do very original work, surprisingly interesting work. Europeans, on the other hand, do wonderful, careful, intelligent, thoughtful theoretical work, but it's not terribly original. It's kind of boring. They make some very fine points that make sense. Some of the Italians, in particular, do some very good stuff. Some European writers have been very careful to move the perspective on death and dying away from medicine. They've been leaders in doing that. But in America, they don't care about that. But they're the first people who interviewed the first 50 people who had near-death experiences, for example, where people after being resuscitated tell a story about going out of their bodies and meeting a bright being of life, have a life review, and meet dead relatives. I mean, the Americans have led that stuff. It wasn't a German who did that. It wasn't somebody from Scotland. It was the Americans. The Americans are doing surprisingly interesting work all the time, in death and dying. But they don't theorise it. So, they just toss that out. So, the Americans do the first three, four, five, or six empirical studies of near-death experiences interviewing 200 people at a time. And then the Europeans and the British write the next 100 books on what it means.

**Coenen:** Can you explain that in a little more detail? Which theorists do you mean, for example?

**Kellehear:** Michael Kearl (1989) wrote 325 pages of facts and figures about death and dying in America. But Tony Walter is probably the only person who's been able to tell us what it means. Because Michael Kearl didn't, we can't keep saying what any of it means. Again, we can say in Britain, for example, the Englishman McManners (1985) has drilled down on mourning behaviour and deathbed rituals. But Philipp Ariès (1981) the Frenchman has been able to interpret what that means in a very grand, if poetic and penetrating way. That means that people read Ariès and not McManners. The Europeans are fantastic theorists. But they don't really do original empirical work. And the North Americans (and some of the Brits) do some very interesting ground-breaking, empirical work, but they're not great at theorising or interpreting. The Brits are somewhere in the middle. That's putting it very crudely, right? But you get the spirit of what I'm saying. I've been working with the Americans for 35 years. I've been working with the Brits for 25 years or so. And I've got lots of friends and colleagues that I've worked with across Europe. That's just been my impression. Of course, you can forget the Canadians and the Australians for the moment – but that's another story. But the bird's eye view from above is, when you move from the USA to the UK, to places like Germany, France, Italy and the Netherlands, thinking around death studies gets increasingly abstract as you move from North America to Europe to Asia.

**Coenen:** Especially this problem that you mentioned that the European researchers might have difficulties facing death in the hospitals or going into the field and speaking with a dying person: This might be highly linked to some thoughts of your books, and I think it might be good if we could talk a little bit more about your research now. For example, in your book *A Social History of Dying* published in 2007, you wrote that we are confronted with increasingly shameful forms of dying. So, certain forms of illness that are common today put our morals to the test because of social inequality, marginalisation and especially ageing. And since you published this book, 15 years have passed. So, now, can we question your original diagnosis? Is it still valid? Has something changed since then? And if so, what and how?

**Kellehear:** So, I think what has changed about death is... I drew on two main empirical sources for that idea of shame. One is HIV/AIDS, and the other one is dementia and ageing. And now, in the case of HIV/AIDS, things have changed radically with the advance of antivirals. But what I left out in that book

was the obsession with a medical rescue. And the obsession with medical rescue parallels that of the experience of dying in care homes and ageing and dying, which is that increasingly, the identity of dying is being erased. It's starting to disappear. Dying identity is most clearly seen amongst those who are suicidal, or those who are in a hospice, or those even who are imprisoned on death row or in death camps, but not so much in ordinary populations that you find now in hospitals, for example, or in care homes. The care home ideology is one of rehabilitation and support for chronic illness. These are not places where dying people are found. But that is where dying people are found. That's the irony. But I think most people still resist the identity of dying, even in care homes where life expectancy after the entry is often so very short. Instead, care homes, to some extent, encourage the residents to think about healthy ageing, which is the prevailing ideology of healthcare professionals. Healthy ageing is the vision there – not healthy dying but healthy ageing. And in the modern world, increasingly, the idea of dying is seen by normal populations as some kind of failure – a failure to grow old. And then what does ›growing old‹ mean? Well, you ask people and find that the answers keep changing. Most people say, maybe 1990s. But when you meet people in the 90s, they're thinking, you know, maybe two or three years more. So, this pushing away of the boundary towards death, where one can recognise the proximity of personal death, is being continually pushed away. This is because I think people feel that somehow dying is a disappointment, a failure, an embarrassment. And that's what originally brought me to use – and I continue to affirm – the term ›shame‹.

**Coenen:** What exactly is behind this term?

**Kellehear:** I do think the phrase ›shameful death‹ is a bit clunky now. When I look back at the words, there probably is a better way to describe this. And if I wasn't a single author, I'd sit across from my co-writer and ask, »What is a better word?«, but it seems to me that to admit to dying is to some extent to admit that you're going to drop out of the race. And in the modern world, it's all about living and competing and comparing. And retirement, in that sense, is also a bit of an embarrassment. So increasingly, people are not retiring anymore. They're retiring and doing different work, or they're going back into the workforce. So again, and again, I'm reminded that if you're very ill, you want your doctors to fight for your life, and you go into intensive care. I think you see this very strongly in places like the United States. And you say, well, the United States is only one country. But remember that the United States is the same size as the whole of western Europe. And that includes population, so we can always say half of the West is in the United States, and in the United States, the hospice movement is not strong. People don't want to die in America. So,

acute care remains very much on their agenda. Advanced care planning is not thriving in the United States. People do not want to die. So, when they go into a care home, they're retiring. Yes, they can talk about death as an abstraction. But they're not much different from people who go into a hospital, they don't want to die tomorrow. The whole hospice pushes for openness, open conversations about death and dying is very, very difficult still, in places like the United States. It's easier to talk to university students about death and dying. And there are millions of studies talking about death and dying with American university students, mainly by psychologists. You don't seem to know that there is anybody else they can investigate other than university students.

But there are lots of other studies about Americans who wish to talk about death and dying. But as soon as you move into the domain of hospitals, acute care, or intensive care, the topics of death and dying quickly slide off the agenda. It really is about survival, about being a survivor. And ›cancer survivorship‹ is a much bigger, or at least a competing narrative to hospice and palliative care in the United States. In Britain, we've just had a major study published (Murray/Amblas 2021) that has shown that although hospice and palliative care is increasing as a choice in the UK, the choice for stronger resuscitative efforts and acute care is outstripping palliative care. In other words, that desire to survive is growing stronger, at a stronger rate, than requests for palliative care. So, what we can still observe, 16 or 17 years after my book came out, is the idea that dying is still shameful. People would rather make other choices than simply accept being a dying person. And I think that is a historically unique position to be in. This is a view we've not seen in the last 100 years. And it's growing stronger. You know, the BBC documentary film-maker David Attenborough talks about different species being endangered. If I was David Attenborough in thanatology, I would say that the dying person – as a social type – has become an endangered species.

**Sitter:** Yes, and you said this tendency is growing stronger. That's a good transition for me to my next question. In your book *The Inner Life of the Dying Person* you wrote: »Dying has a bad reputation« (Kellehear 2014: 1). Most people imagine dying at the end, and so many people believe, you wrote, »that nothing good can come of dying« (ebd.). What you also say is we have to try to change our view. And in this context, you suggest we need to reframe this view. So, what characterises this view that is reframed, and what can we gain from it?

**Kellehear:** So, I mean, we have to rewind this a little bit. One of the exciting things to me always in this particularly narrow field that I work in is the pro-

liferation of policies around dying. So, we have palliative care policies in different countries. We have euthanasia policies in different countries. We even have policies about whether or not there should be a policy around death and dying in care homes or whether there should be a policy for treating people on death row. But what's interesting to me, is that nearly all of these policies have an assumption about what dying is like. And the assumption seems to be gleaned from the popular literature on death and dying. So obviously, if you look at the literature on death and dying, only a minority of that literature is studies of dying. Most of the literature is on deaths, cemeteries, funerals, grief and bereavement, all of that sort of thing, and only a very small amount on the topic of dying. When you look even casually at what most studies in the behavioural and social science have conducted since the Second World War, those studies have emphasised, and underlined, that the experience of dying is a disaster. It's a train wreck. It's an awful experience. And that is a key reason why everybody thinks dying is so overwhelmingly negative. I mean, you can't blame the man or woman on the street for saying dying is awful. If you go and look at the academic studies, it supports what their sense of horror. But that is *not* what dying is like – at the very least – it is not the whole story.

**Sitter:** But then, what is dying?

**Kellehear:** Julia Lawton (2000), a British sociologist, wrote a book on dying. She went into a hospice – and what was her great conclusion? Her great conclusion was that dying is about leaky bodies and suffering. That's what Julia Lawton learned from six months of fieldwork in hospice. That's patently ridiculous. It's ridiculous from a number of points of view. First of all, it's an outsider's view of dying not the insider's view. Her view is all based on her observations. And it was also based on the last few days of life in a hospice. So, the bulk of people who die do not die in hospice – less than 5% of people when Julie was doing her fieldwork died in UK hospices. Everybody else was dying in nursing homes, in hospitals, or they were dying at home. Large numbers of people still die at home. And the bulk of people die at home anyway. Yes, they ›become dead‹ in a hospital for the last couple of days of life, or they become dead at a hospice, or they become dead in a care home. But for the trajectory as a proportion of time – from prognosis to death –, the bulk of people live out their ›dying‹ in their home, workplace, school, clubs, or in front of their TVs. And we've hardly got any studies of that. No one's doing any studies of what dying is like two months out, six months out. So, we're missing all that information and social experience. Then if you look at the way we interview dying people, the history of why we look at them, the way we talk to them. It's always problem-based, we're interrogating their suffering, and we never interrogate

the positive side of dying. So, the social science literature is replete with the word ›fear‹. You could do a content analysis of sociology, anthropology, and psychology and count the number of times the word ›fear‹ comes up. But you can't do the same for ›courage‹. And yet, if you study the cases of dying, across different settings, ›courage‹ is one of the most important words and important experiences. Now, if you understand the reason why I wrote *The Inner Life*, is that I was able to show from existing empirical studies of dying that we have on record from different settings (especially non-illness settings), that for every negative experience or emotion, there is a positive experience and emotion within the experience of dying.

Now, if that was generally well known, generally better understood, two things would happen. One, people would be less frightened. Because we're describing a monster. We're describing something that is complex and balanced. So, that's the first thing. The second thing that would happen is if we knew there were positive things and negative things in dying, not only could we work to prevent some of the negative things, but we could work to promote some of the positive things. So, the whole ideology, and it is an ideology, any philosophy of the good death would become a practical concern. At the moment, the only way we can have a good death is harm reduction. And what I'm saying as a social science person is you're missing half of it. Not only can we promote harm reduction (reducing suffering), but we can also health promote, we can do health promotion, positive promotion, and be able to practically work towards the quality of life. I don't like the idea of the good death. But if we work towards the quality of life, at the end of life, then it is important to know what the positive things to cultivate are? What are the negative things we should try to reduce the harm from at the moment? All we're doing is saying, oh, dying is a disaster. Let's try to manage it. And that is completely a biased and wrong-headed track.

**Sitter:** Does this perspective on positive things to cultivate also go in the direction of a solution-oriented perspective? I'm not sure if you agree?

**Kellehear:** *The Inner Life* is a social science book. It's not a palliative care book. It's not a health-promoting palliative care book. The point of *The Inner Life* was to provide a balanced perspective on the experience of dying that was drawn from different settings that will allow us to get a better, more holistic, balanced picture of an experience we thought we understood. Now, separate from that, if I were to wear my public health palliative care hat, I would say the practice implications are about health promotion, policy development, public education, and services redesign, with complementary work on harm reduction. But that's a separate thing. *The Inner Life of the Dying Person* was designed

as a piece of social science, as a piece of social psychology if you like. And it was meant to address and rebalance the disastrous, negative view of dying that social sciences have traditionally tried to sell to each other and the general public. I challenge that by drawing on multiple sources rather than just the illness type of dying. If you did a study of dying, just studying sociology, sociological studies, you would weep. You would weep because dying is portrayed as so awful. But that's not true. It's simply not true. So, that's why I did *The Inner Life* – to give a more balanced view of a multifaceted experience.

**Sitter:** But nevertheless, I ask myself how practical is this positive view on dying for the other side, which is a little bit outside your book. That means the side not only for the dying, but also for the bereaved. So maybe, I can give you an example. I found your perspective on a balanced view of dying, with these positive things to cultivate, very wise and difficult at the same time. It is difficult especially, for example, when a child realises in the dying process of its mother that it will never see the mother again in the future. So, I asked myself, how can a child as a spectator develop a confident view of dying in this specific context? You are very positive, but how practical is the positive perspective? And what can we do? What is our work especially in the context of grieving children who lost their father, lost their mother – in the future or in the past?

**Kellehear:** Well, there's a couple of things to say about that. First of all, your question and your focus on the bereaved is definitely based outside my book. So, my book is practical. The book is not a piece of social theory. Everything I say is backed up by case studies or examples – everything. So, the first thing to understand is we're dealing with bereavement, we're not dealing with dying. But with bereaved children, they have to understand the difference between the experience of dying and their observations of dying, the ›I witness‹ experience versus the ›eye witness‹ experience, or the emic and the etic. One of the things that many counsellors do with children who have complicated bereavement, serious bereavement, is they get them to try to recall the positive experiences during that time. Because often, the depression and anxieties sometimes swamp and obliterate some of those positive memories. Often there are positive memories there were positive times during the course of the illness of their mother. The second thing is that unless you're a poster child for a materialist view of death and dying, then you have to understand that relationships do continue. And they continue beyond death. So, many children will and can be encouraged to continue their relationship. So, that's the first thing that we would say. There is an empirical basis for believing this as well. So, if you've read *The Inner Life of the Dying Person*, you will know from reading the chapter on ›transformation‹ that between 30 and 80% (cross-culturally) of bereaved

people have contact with their dead again. It is important to remind children and adults that just because you bury somebody doesn't mean that's the finish. Certainly, not finished in terms of bonding, something confirmed by the likes of Dennis Klass and colleagues (1996), and Tony Walter (1999). And these experiences are not technically considered hallucinations by psychiatry (Kellehear 2020). These are cross-cultural, and they're as old as human history. And so, there is a possibility throughout life, to entertain actual (or felt) reunion, as well as continuing bonds through memory, legacy, or soliloquy.

It doesn't matter to me if your final explanation about these continued relationships is based on hallucinations or delusions, or whether it's based on religious experience or mystical experience or altered states of consciousness. Choose your epistemology, it doesn't matter. The fact of the matter is that 30 to 80% of people will reencounter their dead. So then, we have both continuing bonds and the empirical fact that death is not the end of a social relationship. And children, because they are children, often need adults to explain this, that this is not an adult fantasy, this has a research basis, we have an understanding that death is not the end, this is not the same as a Catholic priest saying death is not the end. We are saying in pure social and behavioural science terms, that although mum doesn't look the same anymore, you won't be able to throw your arms around her when you come back from school, yet, you will still have your mother inside you and maybe even outside you. And as you grow older, that relationship will change. And even if you had your mother with you, that relationship would still change. We all have to negotiate changed relationships. And that is the mystery of loss. The true mystery of loss is not physical death. The true mystery of love and loss is transformation and change. And that's how we talk to children when we talk about mum.

**Coenen:** I would like to come back to the point that you want to bring the positive side of dying into play. And I would like to bring it into dialogue with the current situation. Because for two years we have been living in a pandemic situation. Would you say it is possible to bring out the positive side of dying, even in a pandemic? Or are there may be specific problems with this?

**Kellehear:** You know, it's funny, but I've been asked this question two or three times now. First, there's nothing special about the pandemic, not in terms of death and dying. If you die of Covid, you die of something. So, we have a higher death rate due to Covid. But the dying for Covid is not unique. I think what is probably unusual about Covid is that it is a cause of dying that we're not used to encountering. Let me just take this epidemiological discussion for a moment to Britain. In Britain, we lose 16,000 people a year to flu, just normal flu. And now we're probably losing up to 100,000 people, probably another 70 to 80,000

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above that number, because of Covid. So, the difference is, that a new emerging dying as a trajectory, because of Covid, is promoting a short, dying trajectory of 10 to 30 days. But we are much more accustomed to thinking of dying in the modern world as a long trajectory. Dementia, cancer, motor neuron disease, even though motor neuron diseases with a 12-month trajectory are more normal/usual. And all of a sudden, our heads are spinning because we've gone from six months or 12 months to one month or less. That is the new reality really alarming people.

Because with a month or two weeks, you don't have much time to prepare, both the dying person hasn't got much time to prepare and the bereaved people, the survivors, do not have much time to prepare. It's much more like a car accident, suicide, or homicide. So, these kinds of sudden death responses are now being brought into play by Covid types of dying. And we are seeing many more people with very public and alarming forms of grief. But if you mix with people who have survived suicide, or who survived a lost, a loved one from a car accident or homicide, we are much more likely to see that type of reaction. Now we're seeing it in a much bigger public way because of the sheer numbers of people dying of Covid. For dying people, this means that two weeks ago, they thought they were just going to play golf, or they were going to go back to work. But all of a sudden, they're faced with the idea they might die. So, they only have two weeks, maybe three weeks or four weeks at the most. And then they do die. That is a very different experience of dying from one we have been culturally expecting since the Second World War. But remember, there are lots of sudden deaths and short deaths normally. What Covid has done has brought that into centre stage/gaze. And that is counter to our usual public health culture and experience, our public health understanding of what dying is normally like. So, I think this is the difference Covid has made. As far as the positive side is concerned, again, if you sit beside a dying Covid person, 24 hours, seven days a week for three or four weeks, there would be positive things to that. You would see them. If you go in with an interview schedule and ask the dying person, you would probably collect what we've always collected: a series of negative things, unless you knew what to ask for, or unless the dying person was particularly articulate, and was able to talk about the good times as well. And never forget that the last hour of death is usually not interviewable. And we know from resuscitative studies that things go on in that last hour, deathbed visions or near-death experiences, all those kinds of things are challenging to access.

But we've got enough data cross-culturally to know these things go on. We've even got some prevalence data around this stuff now. So, what you see – like love – is not always what you get. And so, there are positive things that go on even in Covid. But they may be sometimes difficult to discern. I don't

want to romanticise this. There are some terrible things in dying, and especially in the last 48 hours or the last week; there is suffering, even in the inner life of the dying person. The *Inner Life of the Dying Person* as a book is not about saying that dying is going from awful to wonderful. All I'm saying is that alongside the suffering, alongside the negative things, there are positive things to discern, discover, understand and appreciate. And Covid is no different. Covid makes no difference at all to that view or actual experience. There are positive experiences in all dying experiences. If you take a longer view and a deeper view, you will see them. The only thing that makes things different for Covid is our historical departure from long experiences of dying to a short one that is unexpectedly occurring today because this is not our usual dying experience. We are used to think that people, except for accidents and suicide, we're used to think of dying as having a lot more warning than the sudden two, three or four weeks things. And this is the shocking thing about Covid death.

**Sitter:** You mentioned Covid makes no difference. But if you're looking more detailed, so in a sociological way, then what we see is the »rise of medical power« (Pap 2021). These are your words. And »what you see is the rise of the public health storyline and how powerful that has become. And the problem with an increasingly powerful medical and public health voice is that community gets eclipsed« (ebd.). And that's really interesting the way you put it here. What can we do to make this community more relevant or more audible?

**Kellehear:** So, what I said there is no contradiction from what I said to Ekkehard. Ekkehard was asking me specifically about the experience of dying. Covid hasn't made any difference to the experience of dying, but Covid has made a difference in the public perceptions and reactions to dying. Now Covid has made a difference in terms of public health politics, or if you like the politics around death and dying. In public health politics, the health promotion people are the left-wing people, they are the people interested in community, they're interested in health promotion, they're interested in community development, social ecology, health literacy, public education, services redesign, but that's only one part of public health. The other part is the surveillance science people, and these tend to be the more conservative members of the public health culture. These are the colleagues who conduct health services research, epidemiology, or bench science work. And right now, Covid has given the power to the bench science people, to the epidemiologists, to the health surveillance people. The health promotion people who are interested in community civil rights, community power, community decision making, the importance of civic society, and civic power, all of these guys have been cast to the margins. And now what we have is, that public health is arm in arm with the government,

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with the state. So now, public health and the government are working almost like inseparable apparatchiks to each other. And this has created problems all over the world. So, we already have not just the anti-vaccination movement, which is a very different thing, but we have a civil rights movement, a group of people who are saying, well, at the end of the day, I should decide whether I want a vaccination or not. And actually, the science about this means that probably if you decide not to be vaccinated, you are at higher risk of using hospital services. But being at a higher risk of using hospital services is not a civic issue. That's a government issue. And so basically, the government is saying to preserve our resources, we're going to compromise your rights, not to be vaccinated. So, this is very serious stuff. And it really talks to the heart of the power between communities and the state. And Covid has raised that problem (again!). And the people who are most hurt in this fight are the people who do not want to be vaccinated, the bereaved and caregivers who are separated from their dying in unfair ways, by the kind of discourse around preserving doctors and nurses and their health services.

There's no reason why communities can't be worked with. And then appropriate arrangements can be made to keep loved ones together with dying people. We've done this in a number of infectious diseases before so there's no reason why we couldn't do it now. And there's no reason why we can't accommodate anti-vaxxers. If we had a different approach to health services for example, but right now, people who make a civil choice are losing their jobs, losing promotions, losing access to venues. These are serious civil rights issues, and they're not glossed over well by seeing these people as ratbags or as marginal people, or as ›conspiracy theorists‹ – all of which are designed to character assassinate and ignore the cultural pluralism that underpins participatory democracy. That kind of marginalisation coming from the government in league with public health officials creates an adversarial political climate, which does no one any good, and is against community development, democratic, and health promotion ethos.

**Sitter:** I guess, this concern goes to the heart of your understanding of compassionate communities (Kellehear 2013), doesn't it?

**Kellehear:** Absolutely. That's it. What happened to that idea of compassion during Covid? So suddenly we are only compassionate towards vaccinated people? What does that mean? Very strange politics indeed.

**Sitter:** I would like to ask two final questions. We are in Covid-19 times, we're just getting faster and faster and more digital and maybe more and more unpredictable. Are there any developments that must be definitely avoided in relation to the culture of death and end-of-life care?

**Kellehear:** I think since the Second World War, we have been battling, we've had a power struggle between communities and civic society, and their professionals. In some countries, professionals moved a long way and toward a more partnership approach to civic societies. And I think the health promotion movement is a very good example of how professional dominance has moderated. We can't have a doctor and a nurse on every street corner. So, it is important that communities get involved in health and safety issues, promoting good nutrition, moderating drug and alcohol intake, wearing bicycle helmets, condoms, etc. It's important that workers and trade unions take some responsibility for health and safety, after all, health and safety are not just visiting a doctor, you should expect it at work and in schools and in the shopping centres and the churches and temples you work in. So, we do see that, particularly since the 1970s, and it's continuing. Nevertheless, at the same time, we are witnessing the gradual encroachment of professional dominance in areas such as grief and bereavement, where the DSM-5, for example, is really trying to exercise greater control over the definitions of grief and loss, and the need for therapeutic involvement, professional therapeutic involvement in our lives, in the matter of something as simple as sadness. So, we win on the one hand, and we lose on the other. It's a bit like a study of palliative care. We are definitely increasing public awareness around death, dying and loss through the hospice and palliative care movement. But at the same time, at the very same time, we are losing ground in that area. People are getting more and more attracted to the medical rescue in intensive care or resisting palliative care resisting or simply bypassing it altogether to opt for medically assisted dying. So, there's this constant tension, even with advanced care planning, which is generally a good thing in principle, but even here it's really a professionally-initiated thing. Advanced care planning is a professional innovation.

It's designed to save the state and professional healthcare resources. It's a constant struggle, and I think we're going to see more of this. And in fact, Covid highlights how easily all our advances and our insights around death, dying, and loss just get thrown out the window with Covid-19 and all of a sudden, we're back to 1950s medical dominance. Their word becomes the law – again. We shut dissent down. Patient voices don't matter. It's amazing how quickly all our democratic rights that we've got and all our public health literacy just goes straight out the window, and medical authority comes screaming back. So, you know this business about community power – and democracy – is a

fragile thing. I'm hopeful because I lead the health promotion movement in palliative care. So, I have to be hopeful. But as a sociologist, I'm always aware that the influence of professional authoritarianism is not very far behind me.

**Sitter:** You are a clinical professor at the University of Vermont. You are offering seminars on dying and death. What is important to you? Or what would you like to pass on and convey to your students in any case?

**Kellehear:** I think the future of the human race is mixed-race people. And I think the future of academia is interdisciplinary work. I think it's important to be proud of being a sociologist, or being a psychologist, or being a historian. But the days when that's all you can be, are gone. Or they're going. And I think we all have to read each other's books now. We have to know what's happening in other disciplines. And we have to be in constant conversation with them now. In the 1950s and 60s, we could just read our own discipline-based books, if you're a sociologist, just read the sociology books, or maybe some social theory, or some other writers who've come from politics or who have come from philosophy. But now if we're in death studies, we have to be in constant conversation with medicine, we have to be in constant conversation with psychology, and we have to be in constant conversation with history. The days of academic monogamy are over.

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