THE BORDERLANDS





Foreword

We will all directly and indirectly experience dying and death in our lives. Yet somehow, they remain mysterious and uncomfortable topics for many of us.

This book is a moving collection of portraits and testimonies that capture the quiet dignity of people who find themselves in the Borderlands between life and death, either due to illness, bereavement, or vocation.

To confront the reality of dying and death, and to consider what it means to you and your attitude to life, requires a high degree of honesty and self-knowledge. To then share this insight and experience with others is a brave, generous, and deeply compassionate act. By sharing of themselves in this way, the participants in this book have shone a light into the Borderlands and provided a unique opportunity to reflect for ourselves on the fundamental question of what life and death means for each of us.

Mark Jarman-Howe

Chief Executive, St Helena

"I am not frightened to die. I have my faith and I'm sure, when the time comes, it will be sorted.

I'm at peace, not frightened. I've had an amazing life. My most amazing thing was having my three children, boys. I did have a little girl, but she died. Life is a preparation for everything. The most important thing of all is my grandchildren, which I have seven, and now I'm a great grandmother.

There's something we could all do, it costs nothing; just being thoughtful and being kind. That comes from my heart and my soul.

If we were all like that, the planet wouldn't be in the devastating way that it is. Just be kind and thoughtful.

I'm 79. Every year is special in someone's life and each decade has been meaningful. We grow with every decade we live, don't we?"

Patricia Brown

Patient b. 4th July 1944 | d. 7th August 2023



"My first death when I was present wasn't long after I'd qualified; it was a traumatic death of a young gentleman. That really impacted how I felt about death because I felt he didn't have a good death, and it probably pushed me to make sure people are settled and comfortable.

Being a hospice nurse gives a different perspective about death and dying and understanding the process, the possible complications, the symptoms. It's a different view to other nursing; in the acute field, you see scenarios that make death not as peaceful as you see being a hospice nurse.

Previously I would have been frightened of dying, but now I'm not afraid of the end stage and not being here. Death and dying are two very separate things and no one can comprehend really what death is. Knowing I'm helping people to be comfortable while they are dying, almost separates it from death."



Abi Harris

Clinical Nurse Specialist

"Working in the Hospice gives me an opportunity to connect with people and feel comfortable.

I speak with the people and I'm pleased to give families support and compassion. It can be very sad and sorrowful. It can be hard sometimes because I get to know the people, but I love this job and how we make the patients feel.

I don't have my own plans for the future but working here now I do think completely different things about life. I try not to have worries in my life and I try to enjoy it and not think much about how everything is.

Because I used to work in different places, I never thought about what was happening in life but now I started this job and think, oh my God, life is too short. It makes you want to do more things. Live today."



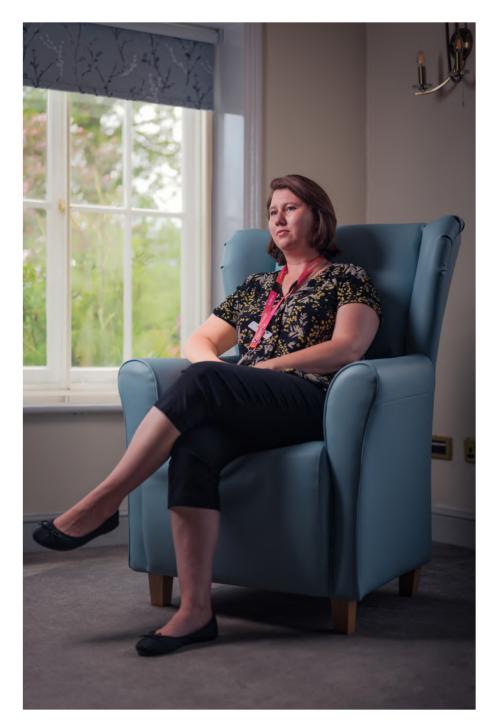
Ania Szczpior

Domestic Assistant

"My gran died from cancer and it wasn't my first experience of death, but it was of the suffering that kind of death can bring. When she did pass, it was very much a relief for us. Some people look at you funny and go how can you say it was a relief, but when you watch someone suffering for two years...

Being at the Hospice makes you realise how short life is, but working here gives me a comfort around death, almost like a peace. People may be in pain and it's really hard to lose loved ones, but the care a hospice gives, and the support and compassion, just makes that transition easier.

It's about where you are and who you're with at the end. And knowing there's somebody there, even though they're not related to you, who genuinely cares about you."



"When I first started at the Hospice, I was terrified of death and dying. I wouldn't read the newspaper death announcements; didn't want to go there at all.

But being here has transformed the way I feel about dying. I don't particularly embrace it, but seeing the support available and how people surprise themselves sometimes of how they can be, means I don't fear it.

Hospices talk about living with dying, not just waiting to die, but making things meaningful for people at the very end of life. There's discussion about where people would want to be as they are dying, and for me, my feeling is I would want to be outside, I love the idea of that.

If something happened to me tomorrow, because of working here, I don't focus on the small stuff. It's about being thankful for what I've managed to do with my life."



"My mum passed away with just us there; my sister, my brother, my dad and me.

I remember every day thinking is it today, the last day?

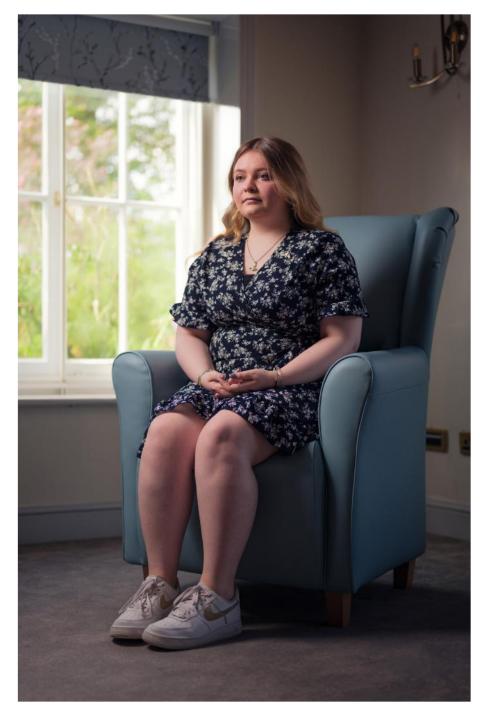
Before I experienced death and dying, I found it quite scary, quite daunting. Even the thought of losing a pet terrified me. Since experiencing death and dying, I've found it quite peaceful. My mum's final few days were very peaceful and I wouldn't have changed anything.

I do believe there's something after. I don't necessarily believe in heaven, but I do believe that everyone goes somewhere and I believe my mum is always here with me and that I'm never alone.

to something new. I don't believe that death is just the end but that you'll come back eventually. And my mum always believed that she would come back as a butterfly, so every butterfly we see, that's my mum."

I believe death is just you passing on





"Death is the end to what we hope has been a long, happy and fulfilled life for someone, and our job is to make it a nice ending rather than a sad one. We've got one chance to make it a good experience for everyone.

How fragile life is. Sickness, illness, death; young people aren't immune. It can happen to anyone, and it happens to people when they least expect it.

It's a great privilege looking after people at the end of their life because it is such a significant moment in the patient's life and the family's life.

It amazes me how open people are to allowing you into that part of their life, and how resilient people are when going through such an awful, challenging and hard time.

But people are so strong and they don't realise how strong they are having to deal with what they're going through."



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"People can have something we call total pain; not only physical pain but emotional pain. Sometimes it's like they're in the in-between stage and not really here on Earth, but their soul is kind of going towards something else.

Death is something that's going to happen to us all, but it's very important how you prepare for that to happen, however hard it may be. I don't think anybody can really prepare for it fully, but planning ahead does alleviate it a little bit.

Working here makes you put things into perspective and live every day as if it's your last. It teaches you to appreciate things and that tomorrow is never promised.

When it's my time to go, I would rather other people celebrate my life rather than mope around, and think of me as someone who enjoys life and tries to do their best for everyone."



Chelsey Bush

SinglePoint Senior Staff Nurse

"My whole perspective of life has changed since working at the Hospice because it makes me realise how short life is and how much we take for granted.

I say to my children now, if you want to do something and you can, don't wait for later, do it as soon as you can.

I always wanted to travel and working here has just made me realise to just to do it if I can, once all my bills are paid and my kids are sorted, I've got food on the table, got no one knocking on my door wanting money. Whatever's left, that's it. You can't take it with you.

You need to live life, it's just so short and precious. You don't know what's round the corner. You could be living a full life and then suddenly everything changes."



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Colette Jones

Cook

"It's sad when somebody dies. When I started working here I was wondering how I would cope with seeing people dying, but then I saw the care we give and how much involvement there is for each person and it turned out that it's not that scary.

Doctors, nurses, physio, family support... everyone putting their pieces into this big jigsaw puzzle. It's so nice to see when I've put a piece into it and I've done my best for that person.

And a good death is very important for the relatives as well, because they will keep that in their memories, every single detail; how the bed was, how the blanket was, how the face of the patient was. Every single thing will stay with them."



"Having the difference between being able to support people through their dying phase in my SinglePoint paramedic role, and then in my ambulance paramedic role having to see the difficulty that family members have coming to terms with the sudden death, can be quite challenging. It can be upsetting for us, obviously.

I'm able to maintain quite a good professional handle on death.

I think that sometimes
I do get caught off
guard, we all do. It does
sometimes just hit me
more emotionally than
you'd expect.

It cements the fact, as I see it much more frequently, that death isn't something to be as afraid of. It's the only thing that is certain and that should encourage you to enjoy the time you have, but not be scared of what's going to happen.

If I can do the right thing and help support these people, then I can be at peace with that."



Dan Richardson

Paramedic

"I've never been as sad as when my mum died.

So at the Hospice, I feel for everybody and I've got sympathy and empathy for them. There's nothing I can do apart from being there for them and I'll do whatever I can do.

My mum had cancer and we didn't know and within two weeks, she died. Whether my mum knew or not, I don't know. We sat with her and she died just before Christmas, and she loved Christmas. It was really, really hard, the hardest thing I've ever done in my life.

I'd been around death before my mum died and I've been around death since my mum died, and I knew that I could work here and be around dying people.

To me, it just looks like someone's gone to sleep. They're at peace. I don't find it at all frightening or scary."



Debbie Miller

Ward Clerk

"I can't answer what death is. I mean, my wife died five and a half years ago. I was there when she died, but I couldn't tell you what death is because she just looked like she'd gone to sleep.

I suppose, unless you've experienced it in any sort of way, you wouldn't be able to explain it really, unless you've died and come back.

I have experienced death in the way the relatives here at the Hospice have when they are in the room while their loved ones pass on. It was like she'd just gone to sleep. She did the biggest snore ever and then that part of her was gone.

She's still with me. The body is now gone. The memories are still there and the memories will always stay there.

But I still don't know, couldn't tell you what death is."



"Being a nurse with the Hospice for more than 30 years has changed my thoughts on life itself and what one should do whilst there is time still left to do it. I hope others may feel it's a time to hold and to try to make positive memories. None of us know what the future holds. We could be here for years and years, or we may die tomorrow.

None of us know what death will be like for ourselves, and it might be frightening at the time because it may suddenly come from nowhere.

So for me, it's about believing and to live life knowing it's important to be with loved ones as much as possible, to take each day as it comes.

> Do positive things, make memories, try to put aside issues that you may have festering within you or arguments perhaps unresolved."



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Di Turner

"I haven't really thought about death or dying because I'm not at that stage in my life where I really want to think about it just yet.

I didn't know what a hospice was before I worked here. I just thought it would be a place for people to go and just relax for a little while and then go home and get on with their life.

It's hard not to make a connection with everybody here because when they're brand new in, I say, 'my name is Harrie and I'll be doing your food orders', and they see me and say, 'hi Harrie, how are you'. And sometimes they gradually get worse and worse and then it gets to the point where this person has unfortunately passed, which is upsetting.

But it's life, isn't it? It isn't always all happy and everything. I know that it's going to happen. We all know it's going to happen."



"Working at St Helena reminds you that end of life can come at any time; young or old. Health and time are so precious.

It is the fear; I don't want to feel that fear. My fear is being in pain and watching your family fall apart. That's just awful. I hope my death is peaceful and my loved ones are only left with good memories of my living and not dreadful ones of my dying.

It's always very sobering seeing someone at the end of life. I am very aware many chapters have gone before, but now it comes down to this moment. I feel dreadfully sad. It's very upsetting when you think that this is the end and I guess that's why we don't talk about it enough.

When you lose somebody close, they are not completely gone. I see little echoes of my dad mirrored in my children; his integrity, humour and warmth."



"I wanted to work at the Hospice after my husband Dennis had died here. When we came here with him, it was fantastic, they were fantastic to us.

The atmosphere was very friendly, like a family, and very personal. It was just so caring, one to one, and anything that Dennis wanted got brought in. We had some lovely meals sitting outside together in the Hospice garden.

And now I'm on the other side, I know what it's like when patients and visitors come in, I know that side of it and what they may be thinking.

I see it sometimes in people, how the cancer or illness can grab hold of you and it scares me in the fact that it can be quite quick. One minute you're OK, and the next minute... that's the frightening bit."



Jackie Greest

Cook and Kitchen Porter

"Death is the next part of life. Unknown, sometimes scary, but we don't really know. It's just the next step onwards.

I like to think that it doesn't frighten me, but obviously if something were to happen now, it would be very upsetting and difficult. It just makes me try to live my life each day as it comes and try not to worry too much; to enjoy life.

Some people are more accepting of death than others and some people embrace it, that they're going to see their loved ones again, if they have the belief and the hope that there's something out there. But most people are a little bit frightened, often worried about being in pain.

A good death is achieving what that person would have wanted, because it's different for everyone at the end of the day."



"I came to the Hospice because of my experience of death and dying with my family. My father-in-law had no hospice care where he lived and I drove there every weekend after working full time, to look after him. My father then was diagnosed with cancer and again, nothing in that part of the world.

So when I moved to Essex and I came to work for the Hospice, my want was to actually give care and love to the dying and the death experience, so it was much better than I had with my loved ones. My mother-in-law was then diagnosed with lung cancer and came into the Hospice when I knew she was dying. And boy, what an experience that was and that will be with me forever.

Having love, care, support, open communication and honesty is a good death to me."



Kimberley Rice

Specialist Physiotherapist

"A good death is pain free, surrounded by family, at peace. It's the end of your life journey. Does that scare me? No, not anymore.

I didn't really think about death too much before, but I think now from personal experience and working here, it's completely different to what I thought it was; better, not so scary. I think that's because of being in this environment and there's so much support with end of life care, palliative care.

The time that we have to care at the Hospice and that we're allowed to do what we like with our patients, within reason, to fulfil their wishes is what makes the dying process better.

We have a lot of fun in a place that people think isn't fun and our patients get a lot of experiences that they wouldn't have anywhere else at the end of their lives."



"Death is inevitable and feels very scary. It's the unknown of what happens or doesn't happen. To me, it's the end of something and I don't know if there is anything after that. Even having worked with a lot of people that are dying, I still have a fear of death. Quite often we will base our fears and our worries around our own death on what we've seen with people close to us.

Facing death is a scary place to be and if you know that you're dying, you very much concentrate on the time you have left.

Death is clearly the end of life, but that person lives on in the memories of others.

That moment is so private and personal, so to witness the end of someone's life, I can only say is a privilege and it's very, very special. And yes, it is sad."



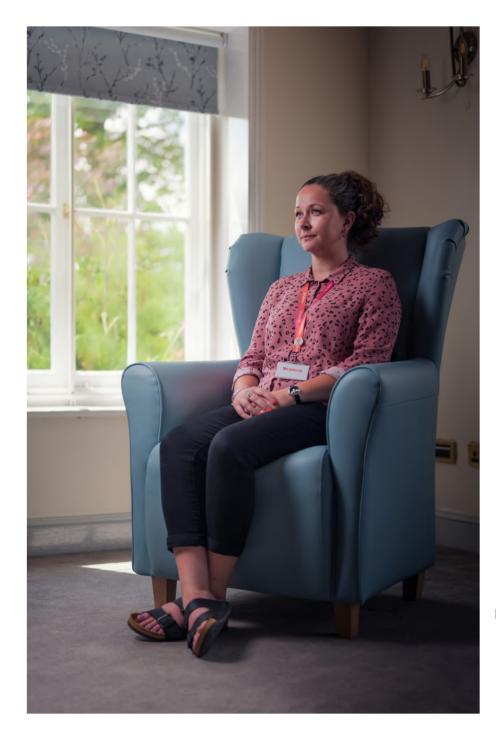
"I did always think about death because my mum worked at the Hospice and then the children's dad is an undertaker, so there has always been lots of death conversations in our house, open conversations.

It doesn't necessarily change my outlook on death, but it just shifts the focus a little bit that actually it could be about getting things done; bucket lists that you could embrace and make the most of the time we've got.

I'm really lucky in a way because when I think of death and dying, I think of peaceful, calm, needs met, because I see the reflection of that at the Hospice in this lovely peaceful environment.

> tell a different story from his experience with it, and that's really sobering."

I think the children's dad would probably



Laura Brisley

Facilities and Health and Safety Manager

"When I think of death and dying, my first thought is my grandma. Working here, I thought I would breeze through it but it was just such a different experience than I was imagining.

I think about dying a lot. If I worked in an office, I would not think about my mortality as much as what I do. But I'm faced with it here every single day. People my own age dying, people my parents' age. It does make me really value life. I always say eat the cake, drink the wine, buy the shoes, because life is too short to not enjoy it and take pleasure in the little things.

And it is the little things about life that are really important, not always the big things. It's the connection with your loved ones and really showing the things that you love.

That shows who you are, shows your personality, leaves your legacy."



"I see death from a different perspective now working here. I do feel more comfortable about death and that actually there's nothing to be scared of. I know a lot of people fear it and a lot of people have feared it but have come to terms with it while at the Hospice.

We don't put a downer on death and we don't highlight death; that's not what we're all fixated on. It's about comfort.

We interact with our patients, we know our patients, they trust us.

We spend only so much time on this Earth, then that ends, and then you possibly go on to another place on Earth or something else, and you move on. I do believe there is life after death and I get comfort in thinking that for my family."



Paula Lund

Senior Healthcare Assistant

"Death and dying, we can't escape from that. It's part of life. Before medical school in India, I would see two parts of life; one is living and the other is death. I felt if you can't save a person, that's a medical failure. That was the culture among the medical team; they're supposed to save lives.

Training and education play a major role and I learned a lot from patients that yes, death and dying is a part of the life, and it's not a failure to say to people, it stops here. The next part is how to make it more comfortable.

I personally know people who had sudden deaths or difficult deaths; all good people and noble people. They had not done anything wrong to anyone, very kind always.

We can't explain all those things and that's where the 'why me?' question comes in."



"It's like a blessing and a curse to care so much. My superpower is in the sense of emotional confidence, emotional insight with people here. I can really feel their pain and I empathise, and it hurts so much.

We don't know what's going to happen next; we've got our different beliefs and faiths and spirituality.

There's such an emphasis on bringing a baby into the world and prenatal care, getting that right and making sure that's lovely. I think that should be the same at the end of life because you only get one chance to get it right.

> Death is the end of something, end of a situation you're in. Death is that they're no longer in their physical form and they're not going to be walking around as a human anymore. Their spirit, I feel, is still there, is reborn almost, but their

someone's life. Death of an era, death of physical form has died."



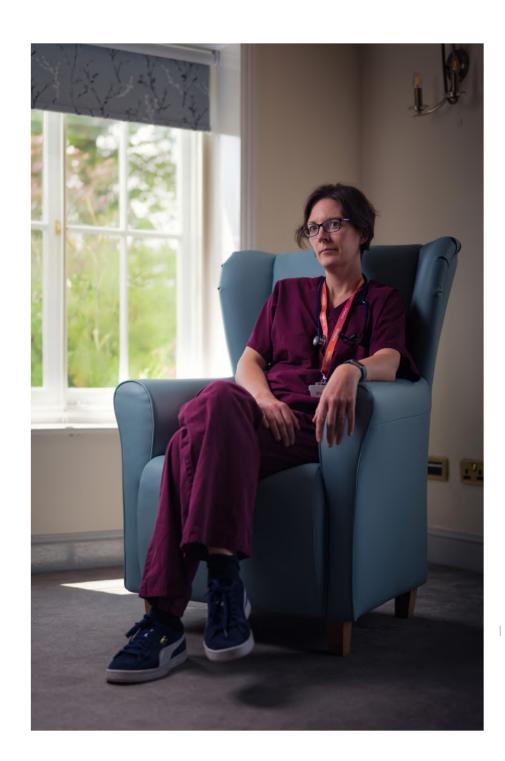


"Death is just a moment. Death is when physically everything has stopped, but dying is what happens in the days leading up to that. I see the time before that as living, perhaps with something that you will die from, but actually living.

It's heartbreaking that there's a finality to it. However ill someone has been, however long and expected that death is, that moment when there is no going back from it, when that final breath has been breathed, that's just catastrophic. It's the end. There will be no coming back from that and that I think, is incredibly sad. You will never stop that.

However much we want to normalise talking about death, it will never stop being one of the saddest things that you will experience; the death of someone you love.

There are times that I go home and I hold my son as tightly as possible. This is what matters."



"With death and dying, I feel as a nurse it enables me to find security and compassion to know that death can be comfortable and there's nothing to be afraid of. It's nothing to fear.

I think my outlook about it changed since I became a nurse, but also the Covid pandemic made me look at my own mortality and put my own plans in place. It made me realise that if you have thoughts and would like people to know what your future wishes are for the event of death and dying, it is important to tell them. None of us know when it will happen; it could be tomorrow, could be 10 years.

I find it an actual privilege to have these discussions with people to allow them to be heard, to allow them to make informed choices and decisions, to hear their voice."



"Surely everybody on the planet knows what's going to happen as time goes on; but what happens when it happens, nobody knows.

A good death would be a quick one. Painless one. I wouldn't want a death to drag on. It's very hard to deal with as a parent or a family member dealing with somebody else's death. It's hard for them to go about their everyday life because of the worry, the concern.

I'm not worried about dying though. It does weigh on my mind as I'm getting to be an older gentleman. It does weigh on me more because of the people around me.

I hear of more and more deaths now as I'm getting older. But I'm not frightened."



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Simon Vick

Maintenance Technician

"I don't have a very fixed idea about what happens after death. When I talk about death I'm talking about the end of your physical body, and maybe there's something spiritual in us that continues on in some way.

Whether that's in a religious sense about going to heaven or reincarnating, or maybe it's in a more earthy sense about the memories that we leave people. Even just simply our bodies giving new life to nature and the world around us as they decompose.

And so I think there probably is something beyond death, but what that means and looks like I really don't know.

Until a couple of years ago I'd never seen a dead body, let alone someone actually dying in front of me. I have discovered it doesn't need to be scary, and actually it can often be quite peaceful. It is a great privilege to be with people as they breathe their last breaths."





Lisa

Patient b. 4th June 1976 | d. 24th June 2023 PHOTOGRAPHY BY ROJ WHITELOCK
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