

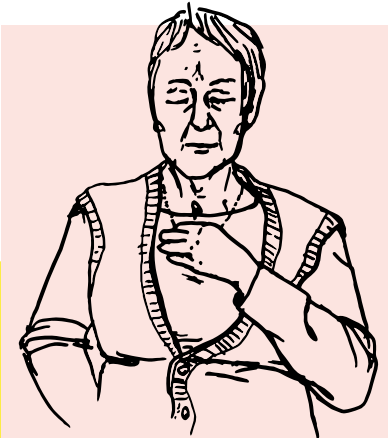
Six Stories

Death, loss and life
in Southwark and Lambeth

MAY 2018



*If your leg is strong,
continue moving*



*Don't underestimate
your ripple*

Better Endings

Creating new solutions for
end of life care and support.

 **Innovation
Unit**
New solutions
for thriving societies

GUY'S &
ST THOMAS'
CHARITY



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Introduction

We invite you to engage with six stories from Southwark and Lambeth. They are personal stories of dying, caring or grieving the loss of a loved one.

We gathered these stories – and many others – as part of the work of Better Endings, a programme led by Innovation Unit and supported by Guy's and St Thomas' Charity.

Better Endings aimed to bring together a diverse group of experts from within and beyond clinical and professional care services to design and develop new solutions for end of life care. We worked in Southwark and Lambeth through 2017, involving over 200 people. We developed a new vision for making things radically better for people at end of life, designing and testing 3 new propositions that model new ways of thinking and working.

But the first thing we did was listen closely to people's stories.

- What matters to us at the end of our lives?
- What troubles and distresses us? What enriches us and brings us joy and comfort?
- What do we want and need from the people and places around us?

We wanted to understand, in a holistic sense, the things that people want and need when they are dying, caring and grieving a loss.

The stories in this volume show us that a 'good death' is not just about pain relief or symptom control. We need human kindness and empathy, with time and support to help us make sense of things; to retain our independence and sense of control; to keep a sense of purpose and to have opportunities to contribute to the world. And we want to know that our lives mattered.

Listening to families and friends of dying loved ones, or people who are recently bereaved, we hear that the pressures and pain of caring are emotional and spiritual as well as practical. The experience of caring and loss can have a profound and lasting impact on health and wellbeing, employment, relationships – on so many different aspects of life.

Most importantly, through these stories we see how much relationships matter. Wherever people find themselves – surrounded by family and friends or without a strong social network – it is the quality of our human interactions that makes a difference. Great relational care from clinicians and professional support services is important, but we need much more than this. We also need opportunities to make sense of things in personal and exploratory ways, as well as regular, every-day human interactions (and whether we are living alone, or in care homes or hospital wards, these things can sometimes be surprisingly hard to come by).

These stories raise important questions for those who lead and work in our existing systems of care and support. They point to challenges, breakdowns and gaps in the way we support people and their loved ones. They also point towards great ideas and new opportunities for doing so much better for people at the end of life.

We hope you find this a powerful prompt for thinking and that you bring these into your discussions towards much-needed change.

Better Endings Team

How to use this volume

This volume should be of interest to anyone involved in current systems of support and care for people at the end of life, whether as part of formal health and care services, or more informal community and voluntary activity.

These six stories can be read as a straightforward volume in private, where you could reflect on what the stories tell you about the quality of people's experiences: what works well? What works less well? What opportunities are we missing for doing better?

You could also use these stories as a prompt for a group discussion, for example in a multi-stakeholder meeting where the aim is to plan for care and support in a locality or region. Ahead of the meeting, each person might read one personal story and come prepared to talk about key things they heard, as a precursor to a shared discussion about emerging insights and common themes.

The final section of this volume offers some additional questions for a much deeper and more wide-ranging conversation – you might also find these helpful in a group conversation.



Collecting the stories

We collected these stories in Southwark and Lambeth through January-April 2017 in our initial exploratory phase of work for Better Endings.

Gathering the stories was a key piece of primary research and insight-gathering for Better Endings. We also undertook interviews with professionals, literatures reviews and gathered a range of outcome and service data for the localities.

The stories gave us rich insight into what's working and not working for people, and helped us to see gaps and opportunities. They became an important springboard for imagining different and better ways of doing things and ultimately enabled us to identify and develop three new service concepts (tested on the ground as part of the programme).

Everyone who shared their story with our researchers did so voluntarily and has given permission for their story to be used in this publication. Some names have been changed.

In creating each story, we typically spent 0.5 to 1 day with each person, in a place where they felt comfortable – at home, in a park, in a café – and in some cases visited people on more than one occasion. Our conversations were personal, informal and exploratory, but supported by a clear research design. In most cases, we brought images and visual prompts to help guide a conversation and to empower interviewees to run the conversation in a way that was comfortable and made sense for them.



Hanging out



Work place



Caring relationships

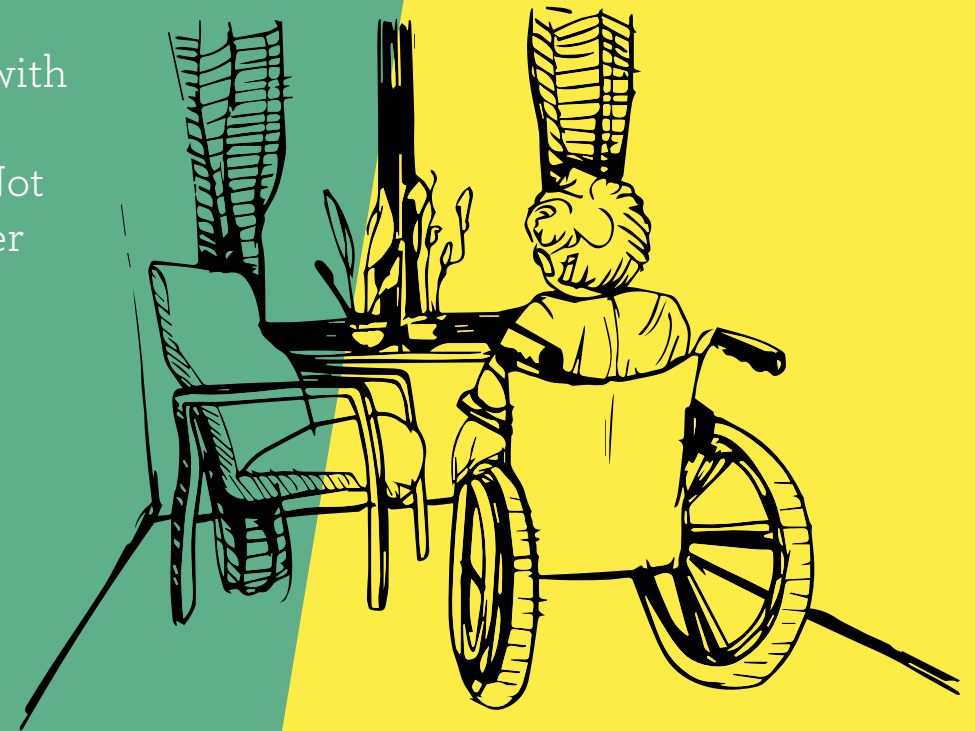
The Stories



Ida's Story

Ida is a chatty and outspoken woman who is not shy to ask for help. She is 85 and has been in a wheelchair for the last 21 years and needs the help of others to get around. She has had numerous tests, but nobody has ever been able to find out what's wrong. Ida was diagnosed with kidney trouble a couple of years ago. Because of her age, having dialysis would be too intrusive and not add much value to her life.

Her husband, Mark, was already in a care home with dementia, and because she couldn't live at home by herself anymore, she chose to live with him. Not being able to walk is the only thing that keeps her in a care home, she says.



Stuck in a place where you don't belong

Ida has been living in the care home with her husband for the past year. This has been very hard on her. She has trouble with the rigid care home routine, which doesn't suit her at all. She is put in her room to get ready for bed at 6pm, but often doesn't fall asleep until 11pm or 12am. She also feels out of place with the other residents, most of whom suffer from dementia and can't offer much in the way of conversation.

“In the beginning, it was very difficult; a lot of them here can't speak. They're just dozing off. It was all new to me. I'm not the sort of person to go in a home. I'm quite articulate. I miss ordinary conversations. Talking about the opera, about anything really.”

“You get institutionalised here. At 11am they come in with the tea and biscuits. The telly is on all the time. At 1pm we have lunch. During tea I have a table on my own. Of course I do, they [the other residents] eat with their hands! The staff know, they call me 'The Lady'. They're kind enough. After my food I'll go up and visit Mark. He has to be fed pureed food. At tea-time it's the only time they come by. They never seem to be lacking biscuits. Other than that, no one comes to see him. He's just lying there, all the time. The TV will be on. I know what he likes. If I had legs, I'd run there and change the channel.”

“One friend I've been friends with for 82 years. We're more like sisters. I never see her now. But every night we have a good talk.” [Ida gets tears in her eyes when she talks about all the places her friend visits]. “She told me she went out to the Isle of Wight. This is hard to hear... I just sit here, in my room.”

“I don't mind going out, but I don't want to go in an ambulance and what not, and then be pushed along the sea front. From the other's point of view it's not necessary to go out anyway, they'll all be asleep the whole time.”



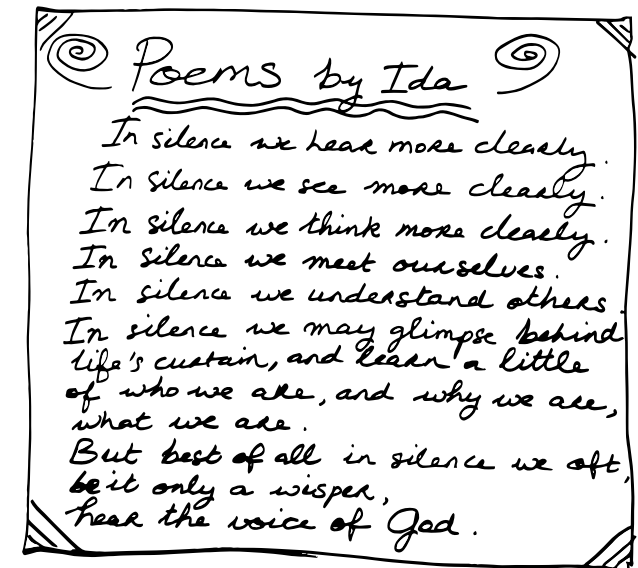
Connections that mean something

The care home is a quiet place, with residents sitting silently downstairs, quite a few with their eyes closed. Ida lives for her trip to St. Christopher's Hospice on Tuesdays. The environment is much more lively and stimulating, and Ida participates in an art therapy class. The lady who runs the art class has become very important to Ida, a confidant.

“Through the church, someone from the hospice came to see me at the care home. We obviously had a heart-to-heart and he noticed I was especially unhappy. My husband doesn't speak. The person from the hospice could see how this all was getting me down. He suggested I came to St. Christopher's once a week. It's been a Godsend, a real lifesaver for me. It's something to look forward to. I speak and actually get an answer here!”

“The first day I was drawing a tree, and soon after that I opened my heart to the art teacher. She knows everything, all the difficulties I'm having. We clicked. The more I saw her, the more I opened-up to her. Once she recorded some of the poems I wrote. Oh, I don't know, they're about anything really. I call them 'jottings from a wheelchair'. The home is full of my drawings. Three poems of mine are up as well, and some of the pictures I made. The art classes should've finished, but I think they're taking pity on me. I have this brain I can still use, and no one around here to use it with. I'm not sure when the classes will go on until but I hope they won't stop.”

“They put me in a group here in the lunchroom. It's so surprising, after a few times they recognised me! They'll say 'Hey Ida!' I belong to that group now. I also play scrabble here. I used to play it a lot, but there's no one at the care home I can play with. Here I found someone to play with – I can't remember what he's called now, me and names! When I come he's got it all laid out and ready. We both missed our scrabble. He plays it differently, so I have had to get used to that. I didn't know there were different ways of playing it! But I know we both really look forward to it every week.”



No time to care

The carers at the home are lovely, but they're understaffed and there is no time for anything other than looking after people's most basic needs. The residents sometimes don't even make it downstairs. They stay isolated in their room all day.

“Often they won't know what I'm saying. When I ask you to get that black bag, you'll do it right away right? I have to tell them twice. I can only have a chat with them when they're busy with me, like when I'm being washed. 'Hot day, cold day,' that's it.”

“I'm there on my own. This home is always understaffed. Some days we don't even go downstairs, there won't be enough staff to get us down. You never know if you're going downstairs or not, if they have enough people to take us out of our room. There are only two night staff. They have nothing to do with the day staff. They don't care, they're just there to do practical things, like changing pads.”



Being a burden

Ida doesn't want to talk much about her family. Some things have gone "pear shaped", and she doesn't want to elaborate on it. She accepts the situation as it is, and feels it's too late to change it. She would rather keep out of her children's lives. She feels that they are still young and should be able to enjoy life without having to worry about her.

“I don't see my daughters a lot. Every couple of months maybe? I'm bad with times. I talk to the youngest about 2-3 times a week on the phone. She'll pass things onto Maggie, the oldest. I don't talk to her due to many reasons I don't want to get into. They don't see much of each other either. I have grandchildren but I never see them. I don't think anyone will come by this Easter.”

“I think it's cruel to let people live until such an old age. There is nothing good about it. It was better before when we didn't get older than 70 due to all the smoking and drinking. If you turn 90, your children would still have to visit you and care for you well into their 70s! I think they should be allowed to live their own lives. I don't have a lot of people that I see and I'm ok with that. I don't want to be a burden on anyone.”

“My mother lived with me, but my children were very young so they didn't mind. And we didn't have money to do anything, so there wasn't much of a social life. We would just go to church. She lived until 83. My father died at 70 of a heart attack. He didn't need anyone to care for him.”

Ready to leave a world that's not worth living in

Ida feels that the world around her has changed beyond recognition. She says she has been ready to die for some time.

“I was diagnosed with kidney trouble. They took me and my two daughters in a side room. There was also a nurse and a social worker and I don't know who else – there was a whole group. We talked about how I might die. I said 'I'm happy to talk about it! I'm prepared.' In fact, I wanted to go. They then send you to a conservation clinic. They see you through to your death. You don't see a doctor anymore, just a nurse. They take your blood, you have a number which goes down each time. It was 33, now it's 11. The lower the number, the worse you're doing. The doctor said, 'If you were my grandma, I wouldn't have dialysis'. I thought, 'I'm going, I should go now.' I'm quite prepared. But I got better. When Dad was in the hospital, they said he should go back home, in other words, back home to die. But he survived. We both did.”

“The church comes to the home. It used to be important for me. I was a member of the Baptist church before the war. It has always been there, it will never go away. But I've been a bit disillusioned lately. There's no way, with all that's going on in the world. Look at what's happening now in Syria. I do watch the news on TV, I'm interested in understanding what's going on in the world.”

“I don't recognise the world anymore. I'm ready to leave it. I'm not upset about it, but I really feel sorry for the younger ones, for the state the world is in. You hear about children growing up without a father, it could be uncle Bill or uncle Bob. And families who are all on benefits, and still they're having children! The world is getting overcrowded. Everybody is so busy, there is so much pressure for people. I enjoy looking at the grass and the trees, I can do that for hours. Nobody stops and looks around anymore.”

Joe's Story

Joe lives in a nice, quiet neighbourhood. But it's too quiet. Since his wife died two years ago, the silence in the house has just emphasised her absence. Joe cannot see an end to his grieving, and partly doesn't want to, because it would mean letting go and moving on. He is constantly looking for signs that his wife is still there.

Joe's wife Melita had lung cancer. Sixteen years before she had survived leukemia, thanks to a donation of her sister's bone marrow. A couple of years ago, they discovered a spot on her lung. Joe left his job as an accountant to care for his wife, and has been retired since then. He has a structured weekly routine that helps him get through the days.

Almost every day he walks to the place where his wife is buried; a lovely walk towards a beautiful, small church on the top of a green hill. He will go to the gym, meditate, go to church and he has just enrolled in a photography course. Once a week he goes to Death Chat to discuss death and dying with other people.

“ Last year I had an operation on my knee. I thought I would die. I heard so many stories of people never coming out of their anaesthetic. So, I got everything in order. I got a new Will done; I want a simple service and the ashes to go with Melita. I have no problems with dying, the pain of living is so intense. It's only the 'how' that I'm scared of.”

“ I can't see the future, but I do things every day to keep going.”



Redefining roles

Joe's household had been a traditional Indian household. Joe was the breadwinner - his role was to provide for his family. His wife stayed at home, raised the children and ran the home. Joe retired as an accountant soon after the diagnosis, so he could care full time for his wife. Now that she is gone, he is learning how to take care of himself.

“My role was to earn money. I never put a foot in the kitchen. Melita cooked everything. I'd come home and dinner would be ready. She taught me how to cook, because she knew she was going to die. She even designed the garden in a way that it would only take me 15 minutes to get it ready! She left me with a support network. She used to go to the cancer help centre to meet up with a group of women going through the same thing. They'd talk, share notes. She told them; 'Look after Joe when I'm gone.'”

“All I have to cope with now is me, and that makes it easier. Before I used to feel so powerless, there was nothing I could do to help her. I was just witnessing this beautiful human being losing everything.”

“I recently started to use a slow cooker. It's brilliant! You just put everything together, and when I come back home it's ready. It doesn't taste too bad.”



Expect a miracle or accept the inevitable

When Melita heard she had only a couple of months left to live, she started to get things in order. She seemed to accept her death from the beginning. Joe wanted to keep fighting. He was unable to accept that his wife was dying. When Joe was caring for his wife, he had a hard time coping emotionally and couldn't speak to anyone about his pain. He wasn't offered any support and struggled trying to take care of his wife who had previously taken such good care of him.

“Acceptance might've given me the right support before. But even though you know what can happen, you just can't accept it, so you won't reach out for help.”

“Up to the funeral, you're busy preparing, you don't have time to think about much else. She was a fantastic wife! She did everything right. She did her own church service booklet, she chose the church she wanted, she chose her resting place. She wanted her whole treatment donated to science so that people coming after her will hopefully benefit from the trial drugs she was on. She was a highly-organised person. She wanted to make sure that everything was done properly. Even in the course of her illness of four years, she never cried once. I remember one day, we were walking down the street. 'You never showed any emotion, any sadness', I said. 'Joe why, what do you want me to do? Do you want me to start to break down and cry and get everyone down, or would you rather I just get on with it?' That was her attitude! Even towards the end. 'No Melita, we've got to expect a miracle!' I found a little card on the street that said 'Expect a miracle'. And I thought God was speaking to me. It became my mantra. Towards the end she was so angry with me: 'What, expect a miracle?' By then she was ready to go. And I was trying to keep her.”

“The way Melita passed was just the most beautiful death. If I could only get 5% of that when I die, I'd be very blessed. We didn't know she was going. But we were at the hospital. At about 6pm she took a turn. Her breathing became very heavy. I nipped out,

don't know why, and then she called 'Where's my Joe?' She'd never call me 'My Joe'. By the time I got to her, she was starting to go. But I held her in my arms, and I said; 'Melita it's OK, It's OK, it's OK.' I had to do that. She was just lingering.”



No one there to listen

During Melita's illness and after her death, Joe fell out of touch with friends and family. He has two sisters who live close by and he sees them regularly. One son lives in New York and the other lives in the UK. He is not close with Melita's family. There were family issues before Melita died, and her sisters didn't see her in the year leading up to her death. On Sunday he goes to church. Even though his faith gives him comfort, he doesn't speak with anyone from church.

"85% of our friends and family have gone since Melita died. We used to be popular, went out dancing all the time. I can't dance without her. But it's OK. It's too interfering, trying to update all your friends."

"What could've helped? Just someone to come over and listen. Just to sit and ask questions. Not a counsellor – it could just be a volunteer; someone who's interested.

It would've helped with the healing. Help to keep her memory alive. It gives me great comfort when people talk about her, acknowledge her. Some people who come over don't ask any questions about her! Like she's dead, gone, finished! That makes me so angry, it's pure ignorance. I'm not going to educate them."

“ Indian families think they're the expert – they were just trying to tell us all the time what to think, what to do. They have their own agenda. It was very hard, and very upsetting to us. They're gone now, I don't hear from them!”



No 'how to deal with loss' handbook

Joe has tried different types of counselling and therapy, looking for a way to deal with his loss. But nothing seems to give him the answers he is looking for. Slowly he is realising there are no answers, and there might not even be an end to grief. Joe feels the right kind of support is missing. He wonders if he could use his experience to help other men to cope.

“All this talking doesn't solve the issue. The issue is how do I deal with this loss? I don't think anyone can give you the support. Yes, they come and listen to you, and yes they will bring religious things into it. I had a load of counselling sessions at St. Christopher's Hospice and I had Cruse [the Bereavement Support Specialists] come here. But they don't have any answers. I can't say it helps. Nothing really gives me support.”

"I know nothing. The experience of loss is so personal. I thought I was an expert on everything, but now I know nothing. There are so many shades of grey. I didn't know what was a normal way of grieving. I was brought up by my mother – my dad passed away when I was nine months old. She only died in 2014, she was 92. I was brought up with loss, but I couldn't understand it. My mom would still cry 23 years later. She never stopped grieving."

"You look for detailed road-maps that say: 'This is where you are.' I've looked all over the internet, read so many books. All I wanted was someone to tell me what book to read, what routine to do. If I could do that every day for so long then the pain would go away. But it doesn't work like that; grief is like a person, it's different each day. You don't know how it will react that day. Once I get over this, when I find a way of dealing with it, I'd like to tell other men about this. That there is no book, there is no plan. And help them to find their own way of grieving. I want to facilitate the healing process. Men don't talk. I think I can help them! I can explain my pain and what helped me; trying to keep her memory alive."

Joe is interested in Buddhism, and finds comfort in meditation



Her presence is the only comfort

Joe keeps looking for signs that his wife is still here. This is the only thing that gives him comfort. There are many coincidences he takes as signs – like premium bonds sent to him on his birthday from her account, or white feathers which fall in the garden. We are sitting in his living room and Joe is half way through a sentence, when he suddenly jumps up and calls out 'Look! Do you see? There's a feather!' He is certain they come from Melita, as she used to collect feathers before she died. Joe hates being home alone, because he notices Melita is not there anymore. He has no trouble sleeping. When Joe closes his eyes, it's like she's right next to him. The place where his wife is buried is a beautiful idyllic place; an old church located on a hill. This is the place he goes when he feels most distressed.

“ My only place of comfort is coming to her grave. My mother's ashes are also here. And there is a piece of my sister's grave next to it as well. My three women together.”

“I can't see my future. My future was built around my wife and my children. And you let go of your children and you think that the wife would always survive the husband generally. For Melita to have gone, every day I question God and ask why. I don't talk like she is gone. I just can't come to terms with the fact that she is gone forever! I go away and then I think, 'Yes I can cope with this, I can do this!' And the moment you put the key through the door, and you hear the silence, then you realise she's never coming back. That's what I can't understand.”



Joe's collected feathers



Barbara's Story

Barbara is an intelligent and independent woman, living in a small flat right next to Tate Modern. She is 86 and has lived here for the last 40 years, always on her own. Her husband passed away a long time ago, and she doesn't have any children. Full of books about psychology and culture, artifacts and objects that are meaningful to her, this flat represents who she is as a person, and is very important to her. She loves writing and has lots of creative work she's produced throughout her life. Barbara talks about wanting to leave her story behind, but doesn't feel she's got the capacity to make this happen anymore.

Barbara practiced as a psychotherapist until her 70s, whilst also dealing with her own severe depression. Having had a difficult past, especially in her early years, she spent a lifetime trying to understand what motivates people. She has recently gone back to visiting a psychotherapist.

Barbara has spent a lifetime fighting the norm, and her identity is very important to her. *"I always took pride in looking different from everyone else. I had a very distinctive style."* She has many stories to tell and doesn't shy away from discussing her own death and legacy.



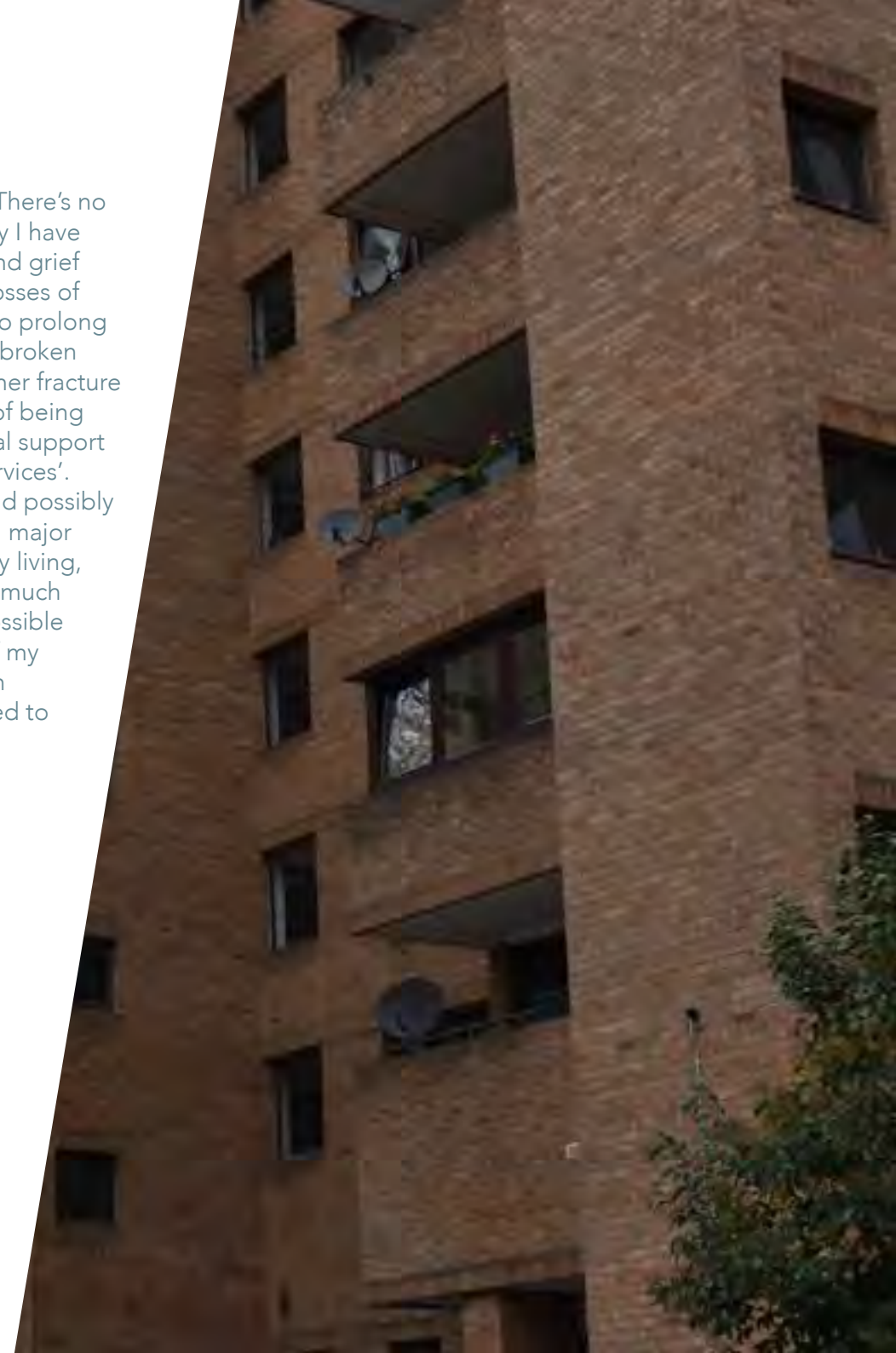
*Don't underestimate
your ripple*

Losing her sense of self

Barbara notices that she can do less and less of the things that are most important to her, and is struggling to find reasons to keep on living. Anticipating a move from her beloved flat, she feels her world is falling apart around her and there is nothing helping her to keep it together. She is fearful of becoming dependent. She would rather be in control of her own death through assisted suicide, which is not something that is currently possible in the UK.

“I’ve got everything in place. I wrote my Will long ago. The only problem is what happens in between now and death. Where can I cope with dying? Who will support me? As I’m falling apart physically and mentally, the world seems to fall apart around me. Everything that’s going on in the world is affecting me deeply. I’m having severe suicidal thoughts. I am going through a very rough, depressive patch. I feel such a sense of shame, too, over not being able to cope better. It feels like all my former competent-enough years never happened. I have collapsed into a helpless, crying baby again.”

“My life frightens me. I feel stuck. There’s no purpose for me to go on. Gradually I have come to accept that my sadness and grief are quite natural reactions to the losses of growing older and I have no wish to prolong this. My anxiety over tripping over broken paving stones and sustaining another fracture has increased, along with my fear of being rendered housebound with minimal support from the already overstretched ‘services’. Rather than endure more of this and possibly worse (and not being inclined for a major clear-out and move into community living, no matter how ‘desirable’) I would much prefer to be helped to die, as is possible in Holland. This means at a time of my own choosing, hopefully in my own much-loved little flat, kindly enabled to cease breathing with the help of a doctor.”

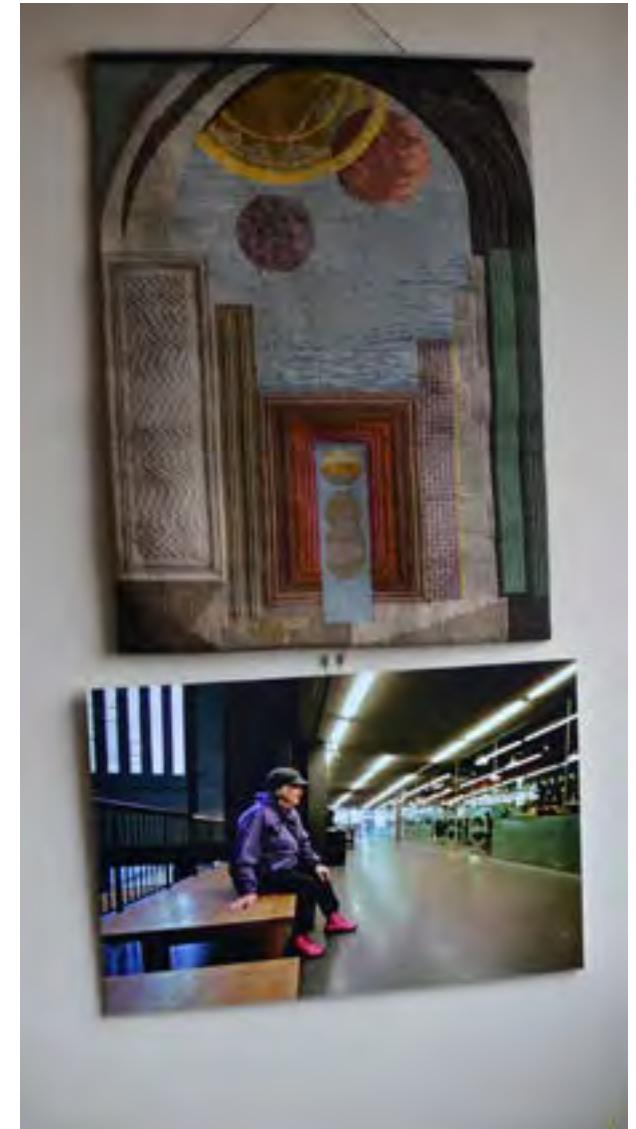


Dehumanising services

Barbara has worked in health services her whole life, first as a psychiatric nurse and then as a psychotherapist. She has a lifetime of experience and gets frustrated when her psychotherapist won't listen to her opinions. The interactions she's had with services over the years have left very bad impressions.

“One of the greatest terrors I have now – this is why I wish I were dead – is having a fall and a fracture, and then there not being sufficient services to help me.”

“I had a fall and ended up in the hospital. There was a fight between the hospital and social services over who was going to be responsible for me with my leg in a plaster and no family or neighbours around to help. I was told to phone the social services on arrival home. They asked me two questions. Never mind a ‘How are you Mrs. Robson’? The first one was, ‘Do you need a commode?’ and the second one, ‘Do you need meals-on-wheels?’ I was still in shock from having just arrived home! Wasn’t used to using a crutch. Here we have an example of de-humanised social services. Well, I told her, ‘No, thank you!’ I don’t want a commode, because I’m sure I can limp to the loo. I don’t want meals-on-wheels because I tend to eat raw food, like salads and soups. I don’t like what they have. They said, ‘Well, if you don’t want that, there’s nothing we can offer you.’ Are you’re saying you’re making an assessment over the phone, not even coming to see the circumstances of where I’m living? She immediately responded, ‘I will send you a complaint form, and if you can tell us how to run our service better, we’ll all be very grateful.’ I’m not making a complaint! I’m trying to adjust myself. I’ll have the plaster for six weeks at least. I’m trying to work out how to manage. She responded: ‘Our services are in meltdown. I will contact you in a month’s time to check.’ I might have said at that point, ‘What, to see if I’m still alive?’ How did I manage? This chair has wheels on it. I managed to scoot my way around through six weeks of solitude.”



Dealing with loneliness

Barbara has a strong personality. She's learned to not make excuses for who she is and what she stands for, and anyone who tells her otherwise is not worth having in her life. Most of her friends live in places far away. She's lost touch with her family and doesn't have many people close by that she can count on.

“My family want this flat. They're not going to get it. I refuse to be the equivalent of the Victorian great aunt, who's supposed to be grateful for their crumbs and leave them this flat.”

“I have nothing in common with what I call 'Ordinary People'. I don't enjoy gossip. I don't have grandchildren to brag about. I'm on a different wave-length. I feel like a thinker between un-thinkers.”

“I'm very attracted to your age group [people in their 30s] and get on well with them. I call them my surrogate grandchildren. But unfortunately, although they are fond of me, they're full with their own lives and they go off. So, I repeatedly have to cope with an empty nest, you see. I don't have friends I can rely on here. None are geographically close.”



The view from her flat

‘Turning shit into manure’

Even though she had a very difficult life, Barbara has found that all her experiences can offer something from which others can learn. It's important to her to feel her life had a purpose. She is looking for any opportunity to leave a legacy of expertise and experience.

“I want to leave my story. Even though it was all shit. You can transform shit into manure. I'd like my experiences to help future generations. The most important symbol for me is the pebble, falling into a pool of life. It makes a ripple, for better and for worse. Don't underestimate your ripple! I'll remember the ripples I've caused in my life. This helps me when I'm feeling hopeless about the state of the world, and that I had no impact on improving it. It's knowing that you're not alone. There are others who think like me.”

“I so want to help people to understand that old age – especially the gift of time that retirement offers – can have great meaning and value both to the person and their wider network. Simply sitting still and drawing on the depths can prove like treasure found at the rainbow's end. And this far exceeds any possible pot of gold, for this rainbow-treasure can only appear when sun is combined with rain. I think this may be 'The Pearl of Great Price.'”

“My view is that death is a natural part of the life-cycle for all forms of life. So too is the suffering of sadness and grief as we gradually come to face the truth of our mortality. But it's lessened, so I've found, when shared with empathetic others of every colour, creed or class. How shall our species evolve if the old are not willing to make way for the coming generations? What can our lives mean when we lack all sense of being a part of history? Death need not always be feared or seen as a tragedy, something to be continuously fended off, when we've lived our brief span as well as possible and given of our best.”



Brian & Sarah's Story

Sarah has worked at Ace of Clubs, a support centre for homeless and vulnerable people, for the past seven years and volunteered there for sixteen years. She says, "It's very tough. But I love it!" Ace of Clubs is open every day from 12-3pm. During this time, they serve delicious food, give advice and support, deliver health care, and organise events and workshops. But Sarah's role goes way beyond this. She regularly goes to court, police stations, hospitals and hostels. She organises funerals, wakes and memorial services. She lives and breathes this place – nothing would happen without her. Many people who come here are probably still alive because of Sarah.

Brian comes to Ace of Clubs every weekday. When it's closed, he hangs on the street with friends, drinks beer and sometimes places a bet. Brian has been an alcoholic for most of his adult life, which he sees as something he can't and doesn't really want to heal from. "When I feel it's going off the rails. I'll be off drink for a couple of months, but I know it'll come back, it's like a recurring illness." Brian's alcoholism is the cause of a serious heart condition and has been the main reason that he's never been able to hold down a job or a relationship for long ("I always seemed to cock it up"). Brian also has prostate cancer and will start radiotherapy soon.

Brian has four children with two different women, but he doesn't speak to any of them. He knows he might have grandchildren, but he doesn't know how many and has never met them. Even though he hangs out with a group of friends on a daily basis, Sarah is the person he opens up to. He talks to her about everything. "I don't believe in a religion, but Sarah is an angel." Brian has lived in the same house for 20 years. It is a vibrant place, filled with pictures of art and clocks. His house reflects his mood – when it's a mess, he knows he has to get back on track. This usually includes a trip to a Drugs and Alcohol Service.

Fear of being forgotten

Brian has a fear of death. He's had it his whole life, but it's got worse since turning 60. It's not the act of dying itself that frightens him, but the feeling of not having accomplished something of which he can be proud. It scares him that life will continue after his death and he won't be part of it in any way.

“I’m dying, I’m in the last lap. I’m not religious, so this is it. I’m not happy it’s coming to an end. It’s the last chapter. I feel like I haven’t done enough with my life. Never really figured out what I was good at. I’m afraid of missing out when I’m dead; all these millions of years that will come after me! So much already changed since I was born.”

- Brian

“Life is short term for these guys. When someone doesn’t come back, they’re easily forgotten. No one asks for them anymore. It’s assumed they are either in the hospital, in prison or dead. They become a rumour.”

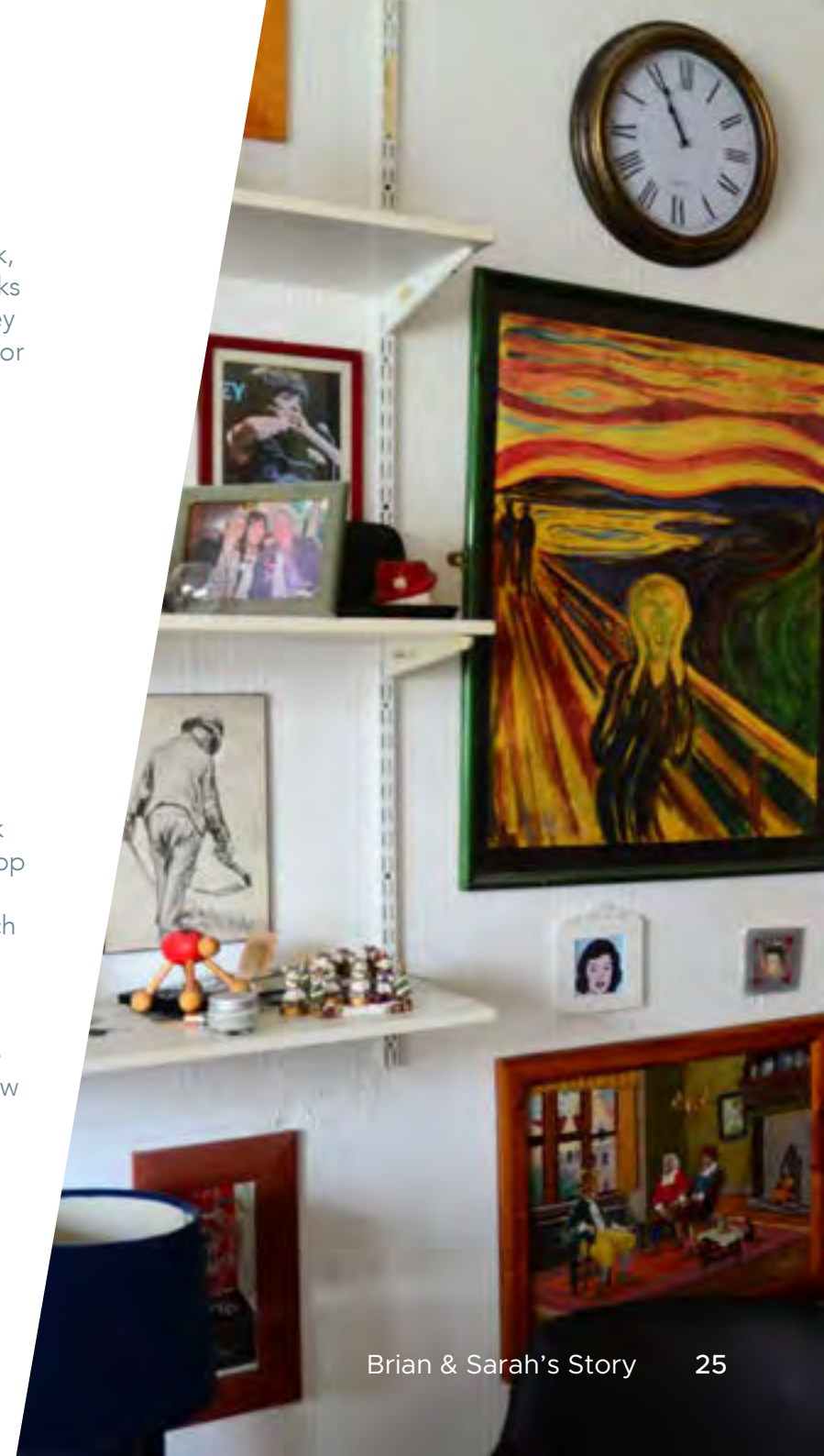
- Sarah

“When I have to arrange a funeral, I’d love for the priest to be able to say something personal. They haven’t always sat on a bench, they’ve done stuff! But getting them to say anything positive about themselves is difficult. The worthlessness they feel.”

- Sarah

“I help them look forward, not look back. We did this great CV workshop once. Some of them came out and said: I haven’t realised I did so much in my life! Can we do the same for them to tell their story? It should be something they’re proud to be remembered by. To have a positive view on life, is having a positive view on death.”

- Sarah



Struggling to see purpose in life

Brian isn't in touch with his family, because he doesn't feel he's worthy of being in their lives. He thinks they are better off without him. Sarah tells us that many homeless and vulnerable people feel worthless and ashamed of the situations they got themselves in. They don't want their loved ones to see them like this and so have pushed them away. This makes them more likely to be isolated, but also less likely to improve their situation.

“It makes me think about what I've lost. I believe I have a few grandchildren but I don't see them. I tried to get in touch – I sent a friend request on Facebook. But my son never accepted it. What else can I do? I'm not going to try more; I'm not worth it.”

Brian

“I'm a smart guy! If I were middle class I know I would've been successful. I needed more leadership. It all went away when my dad died [when I was twelve]. I'm apathetic and lazy.”

- Brian

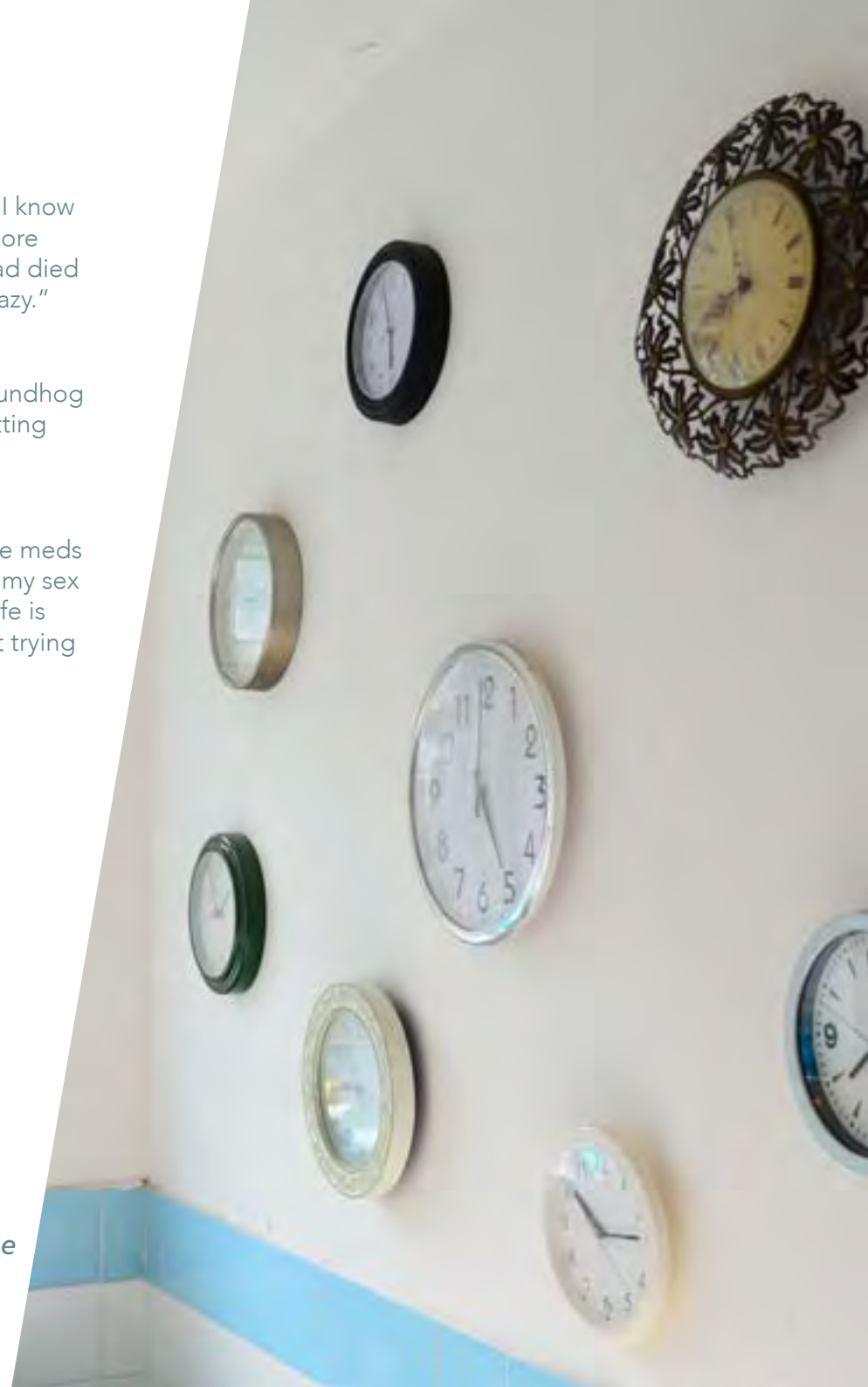
“To be honest, every day feels like Groundhog Day. Have you seen the film? I'm just sitting out my time.”

- Brian

“Can I tell you something personal? The meds I have to take for the cancer gets rid of my sex drive. It's a blow to the body – my sex life is over. I don't feel like a proper man. Just trying to keep afloat.”

- Brian

Brian's home



Living with so much loss

Brian's father died when he was twelve. It had a huge impact on him. He lost his role model. He left home a couple of years later because he couldn't get along with his mother's new partner, and started drinking heavily from then on. Since the loss of his father, other deaths have affected him less, including the death of his mother. Death and loss have become common features of relationships for Brian. Every week or two he hears about another good friend who has died.

“My dad was the family. When he died, it split the family up. We found out he was running two families. I had an extra three brothers I found out about! Don't talk to any of them. They're all cold people. People say to me: 'You go on about your Dad!' But I just feel it's gonna be me one day. Why bother with life? Dust to dust.”

- Brian

Not too long ago Brian went to a funeral of a friend. The experience hit him hard and made him contemplate his own death. “He was proper homeless. They found him in the carpark. They put funerals on the notice boards at Ace.” “I was the only one there, nobody turned up! The priest asked me if I wanted to read a prayer; I felt I had to. Is this what it comes to? There were no flowers, it was glum. Eventually some other guy showed up who was drunk.”

Sarah has known Alex, a homeless man, for years. He is one of her favorites, and he's currently in the hospital with liver failure and has just a couple of months left to live. She is wondering how to plan for his death, especially how to tell his closest friends. “I know they can't cope with these things. They'll say they'll go visit him, or go to the funeral, but they won't do it. His friends don't want to admit he's dying. It's facing reality. He went into hospital because he drinks too much. The people he hangs around with drink too much as well. One of his best friends, they sat on a bench for years together. They'd just sit and drink. I told him to go visit him. I said, 'You don't know how long he's got left to live and you'll regret it if you don't go.' He didn't want to go, said he didn't like hospitals. But last year another friend of his was found dead on the pavement. He took that really bad. He did go. And, well, he stopped drinking! It could've gone two ways: He was either gonna drink himself into the grave, or he was gonna stop. And he did: he shaved, cleaned himself up.”

- Sarah

“Their deaths really upset me. I think 'If only I'd done more...' But when I think rationally, I know they're grown-ups and should be responsible for themselves. But still.”

- Sarah

Who will care?

Sarah is much more than a manager to the men who come to Ace of Clubs. She is often the closest thing to family that they have – or at least the only person who sees them regularly and supports them. When you listen to Sarah's stories, you begin to understand that she is a carer to so many people at the end of their lives.

“ Frank collapsed on the street when I was trying to get him to his hostel. I took him to the hospital. He died alone – got a fit when he went to the bathroom. He always had fits, and had developed brain damage from the many falls on the floor. When he died, his mum was most upset about the fact he died on his own. That has always stayed with me. He was a lovely guy – a loner, very intelligent. He would sit on the street with a cup in front of him, but always reading a book. We'd have long chats about what he'd like to do, where he would go.”

Sarah

“I'm their mother. Sometimes their wife. It's a very maternal role; reminding them to take their meds, but also that they have lives worth living. Mainly it's just about sitting there and listening to them. I don't judge. They tell me about their drug dealers, their experiences with police, anything they like.” [Laughing] I'm the next of kin to quite a lot of them! Maybe a dozen?”

- Sarah

“What supports me? My faith. I talk to people in my church. But mainly I don't like talking about what I do. Don't want to brag. I just do it. The guys I work with are the same as the rest of us. But they need my support – they have nothing and no one. If I have a meal and they have nothing, I have to be the giver. I don't think about it.”

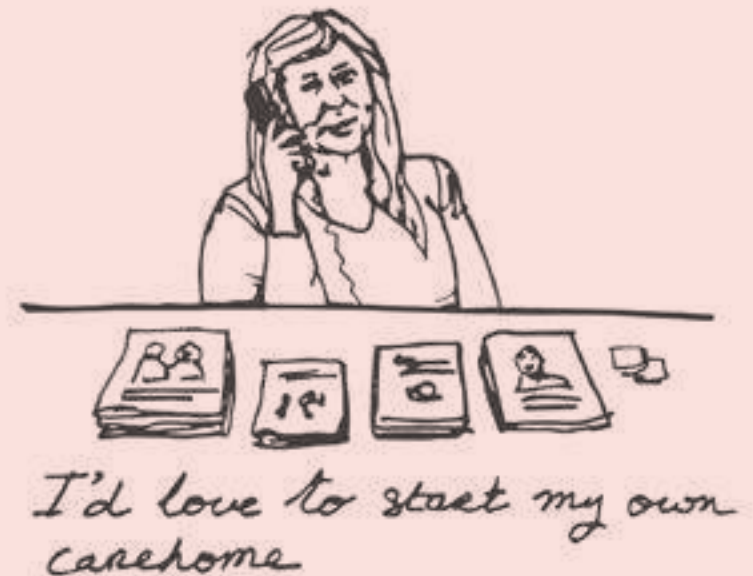
- Sarah



Charlotte's Story

Charlotte is 50. She works at a community centre and has been there for the last sixteen years. Her mother is 83, frail and getting closer to the end of her life.

Charlotte's mother was diagnosed with cancer at 80 and is now clear of the disease following chemotherapy and surgery. Her biggest challenge now is severe arthritis. She has been unable to walk for the past five months and struggles to get out of bed. Charlotte's sister has always lived with her mother and is now her main carer. Charlotte visits every day for lunch, helping with many of the practical things.



Fear of losing control

Charlotte's mother is a strong woman who is used to taking care of herself. It is hard for her to accept that she needs the help of others. As she is slowly becoming more dependent, she fears losing control and her sense of her self.

“ My Mum doesn't want you to know her business. My sister is a carer, but doesn't get any carer's allowance! She doesn't want to apply for it. It would mean my Mum giving my sister her details to go and apply for it, and my Mum won't have it. She won't give out any of her personal information. It's not like you have a million pounds Mum, you've got nothing! There's so much she could be part of in Southwark, so many activities. She's missing out on all this, because she has to use her bank details and she just refuses! My Mum doesn't want people to know her business. She doesn't want to lose control – it's her lifeline.”

“Where my Mum lives is no good – it's not suitable for her. The house has stairs, everything is upstairs. It's a nightmare. My family won't address it, they've lived there for so long. Just to get her up and give her a bath takes so much effort. She should be cared for in a proper home. But my Mum just doesn't want to leave her place. As it is now, she would need a stair-lift, a wet-room put in. Now that she can't walk, it's a whole bigger game. But they won't do it. They live in cuckoo land! It's heartbreaking, she's not the woman that she was. It's hard to put your foot down and say, 'You're not in control anymore, you'll have to let us take care of you!' But then she'll say 'P*** off!' I can't intervene that much. She doesn't live with me. It makes me feel guilty that I don't see that much of my Mum. But I have my own family I have to take care of.”



Who is the expert in care?

Charlotte and her sister haven't had good experiences with professional carers. They rely on additional support while Charlotte's sister is at work, but they find this very unsatisfactory. The carers make them feel like they are just getting a job done. Everything feels very transactional. There is often not much personal connection, or effort to build relationships.

“Some carers are lovely, but some are just so... All they'll do is sign the book, say they're late for the next one and don't do nothing! Sometimes they don't even turn up. A couple are absolutely horrible. Mum will tell them off constantly. These two big women, when they lift her up they really hurt her. And when my mum says so, they just laugh at her and say, 'You're too skinny!' My sister's complained many times. She complained to the company, but then they sent the same one back again!”

“My Mum is getting incontinent. She needs large pads, but they only want to give us small ones. They came to measure her – just to tell us what size pads she really needs! These smaller ones are tight around her belly. And she's sitting down all day so the bigger ones will be fine - just take my sister's word for it! We probably know better what pads she needs! All these practical things take up so much time, time we could spend with each other.”

“The consultant we spoke to said that she shouldn't be resuscitated. He said it's down to him to decide. Just because she's losing her mind, you're gonna kill her? I said to him, 'If my Mum has heart attack, I want you to do anything you can to bring her back to life.' When I spoke with my Mum about this, she said, 'I'll come back, I won't die!' My Mum may not go out and walk about, but she's got full control of who she is, of her life, her money.”

Preparing is accepting

When the end is unclear, it is difficult to accept that it is coming and to know how to prepare. Charlotte tries to talk to her Mum about things that need to happen before she dies, such as paying for the funeral. Apart from practical things, Charlotte and her sister don't talk about how they're feeling and what it means to care for a mother who is deteriorating. They're just not that kind of family.

"My sister and I don't really talk, we just get on with it. The only things we talk about are practical. We're worried about the finance – sorting out the funeral, that sort of thing. We want to have it the way she wants, but when we try to talk with Mum about it, she'll say 'I'm not going anywhere!' Or sometimes she'll say, 'Just put me in a basket and throw me in the Thames.' Then I say, 'No, because I'm gonna stuff ya!'"

“ It drives me mad! How are you supposed to achieve anything? My Mum doesn't want to talk about anything. But it has to happen, because she could die at any moment! She's recovering from cancer, but has a bunch of other things and is in and out of the hospital. Sometimes, I would just like to take her money and pay for the funeral. If she dies, I don't have the money to pay for it, and neither does my sister. And if Mum passes away, we can't access her bank account. When I talk to her about this, she'll say, 'You don't need to know how much money I've got!'”

Isolation is deterioration

Charlotte's mother has not left her bed for the last four months. She used to be a very active woman, but losing her physical abilities has drained her motivation for life.

“She has sort of given up so to speak. It's very sad. She's got so skinny, she is so fragile. It's a shame, she's got so much going for her! My Mum loves dancing and all that. But she's forgetting things now. I just want to know, 'Why have you given up, Mum? You're forgetting how to use your body!' I just wanna shake her and say, 'What are you doing!'"

“You're missing out on stuff, Mum! I want to take her to Blackfriars. All these events that are happening – she could spend every day here, chatting with others. But my Mum will say, 'I don't wanna talk to all them old people.'”



Adebola's Story

Every Tuesday and Thursday at 9am, Adebola starts cooking for around 100 people from a community kitchen in Peckham, not far from her flat. Serving starts at midday. People book via a website and they come and eat together, or they pick up food to take home. She charges £1 for a hot meal. The people she serves are “needy and famished.” Some are homeless, but others are not. She feeds anyone who wants an affordable hot meal.

Adebola wants to talk about dying. She knows a lot about grief from her own experience, and also from the years of community and charity work she has done to support bereaved people – especially widows, like herself. In 1978, Adebola and her husband came to the UK from Nigeria to study. He was studying teaching, and she was studying social work. They returned to Nigeria and had six children together. Then, twenty years ago, her husband was shot and killed. It was a random act, and she doesn't know the identity of the perpetrator or the reason her husband was killed.

Adebola found it difficult to grieve and to pick up the pieces of her life. She returned to the UK for what she thought would be a month-long holiday – a chance to get away from her pain and to do something different. Instead she started to lose her vision, became very ill and was hospitalised.

When she regained her health, Adebola thought differently about her loss and the life she should lead going forward. She wanted to reach out to other widows to share her experience; to help them through their darkest times. She now sees her husband's death in these terms: “God was preparing me to minister to widows.”

Adebola remained in the UK. Since 1999, she has supported (emotionally and financially, through charity work) over 200 widows in the UK and in Africa. All too recently she suffered a terrible loss when, just before Christmas, her daughter died in Nigeria. She had just given birth. Adebola's grandchild is now four months old.



Being there in the dark hours

Supporting people in their 'dark hour' is Adebola's vocation. It's what has driven her life and given her a powerful sense of purpose through the two decades since her husband's death. She connects to people through her church and through other community work, making herself available on the phone 24 hours a day. She listens, offers consolation, prayer, food, encouragement and the wisdom she's derived from her experience.

Adebola has a clear stance on grief: crying is good because it's important to "get the pain out". But she's also keen to nudge people beyond the sorrow and confusion, when necessary. She says she knows what the Dark Hour is like: "The hour when someone precious is taken from you, and you ask yourself, why? Why did this happen? Why me? Where is God?" She talks about the depression that can so easily come to you, when you can't find answers to these questions and get stuck in that place.

“It's not easy to get out of your loss. If you don't encourage yourself, you will find yourself where you don't belong. I say to people, why are you doing this to yourself? We need to find inner peace, and it's only you who can give yourself peace.”

“You need to calm down. In every situation in life you need to calm down first.”

“The widows are all different. Some just sleep. Some won't eat. Some cry, cry, cry, cry. No one has time for them. I'm not working. I have time. I encourage them, tell them what they need to do. You lost your husband? Number one, sleep. If you don't sleep, you'll never sleep again. Don't use tablets to help you sleep. You have to live through your grief. Just yesterday I said to someone, please you need to sleep. You need to relax. Everything will be ok. When your wife died or your daughter died, it is just a situation. Situations come and go.”



*If your leg is strong,
continue moving*

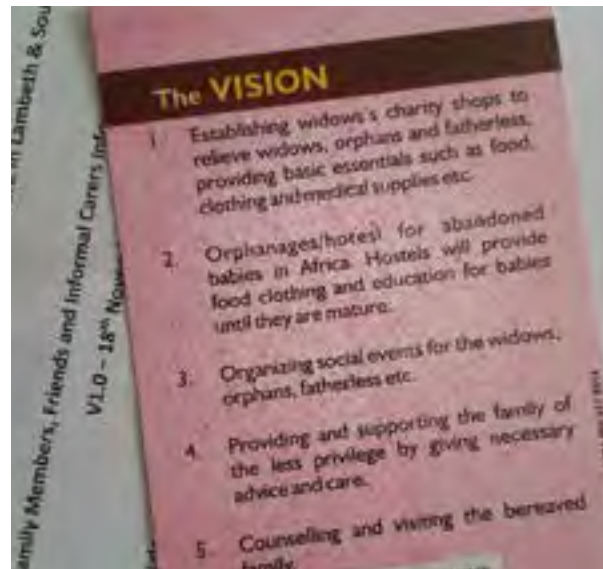
Good things come back to you

One of the things Adebola notices about life in the UK is how lonely and isolated people can be. She reaches out to other humans – neighbours and strangers – when she sees pain or struggle or need. This is the way she lives her life. She knows she makes a difference, and that everyone can make a difference. While I am visiting, we deliver food to her elderly and very frail neighbour. He is 90. Adebola has been bringing him food for five years. She notices that when you do good things, good things seem to come back to you.

“Five years I’ve been giving lunch to my neighbour, so everyone knows me. The council knows me, social workers know me. When the daughter came, wow Adebola! ... When you are doing good to people, people do good to you. See this house, and furniture? I didn’t buy anything. Everywhere people are blessing me.”

“We are not only cooking for the homeless, we are cooking for the community. People are very busy. They are looking for money, money, money and they don’t take care of themselves. This is what the kitchen is for - if people are working, doesn’t matter. Come, take food. People who are drinking - they don’t eat. People smoking - they don’t eat. They all need a hot meal.”

“There are a lot of people who need help in this country. More than Nigeria. Why? In Nigeria we work with the community - your problem is my problem. I know the United Kingdom, they are very good. They do everything in humanity, ‘A’ for effort. But loneliness! Loneliness is here. In Africa, it’s not like that.”



If your leg is strong, continue moving

While she grieves the recent loss of her daughter, Adebola continues to support other people who are bereaved. Returning to responsibilities, consoling others and her faith in God help her to find her way. She gets up, cooks, does exercise, wears glorious colours and bright, red lipstick, and ministers to other widows. She tells me that everyone who knows her well is looking out for her – paying attention to how and whether she is coping. Some are perplexed at her attitude and behaviour: she is the one encouraging others to stop crying and to find their peace.

“When she passed away, I looked at myself and said, Wow: this is another challenge. I looked at myself and I noticed, you always receive the bereaved family, so let me talk to myself again now. I was encouraging the family in Nigeria that nobody should cry. Everyone should calm down. Everything will be okay and what we need to do is thank God for the baby. This is the baby she left behind. She's four months old now.”

“When I lost my daughter, people are coming, everyone is coming. They will come. But after the burial, there are only a few people you can see. And this is the time you need people. This is the time you need support, and this is why people get depression. This is the work I am doing.”

“When I minister, I can't go there wailing. Me? I can't do that. I have to have the courage. I go there to encourage them. Even if I want to cry, I can't do that. I pray.”

“My husband was shot and killed with his friend. We don't know who killed them. I wondered how am I going to survive with six children? My daughter died in December. A double bereavement. But I tell you why I am able to sustain: as my Pastor says, 'If your leg is still strong, continue moving. Continue moving in life.'”

Discussion Prompts

Having read these stories, you might now like to consider the themes that emerge from them with colleagues in a group.

What new things did you notice about people's experiences at end of life?

What challenges and gaps in current systems of care and support feel especially important?

What opportunities are we missing for doing better?

You'll find below a set of questions for deeper discussion that emerged as important for us across all our research and engagement activities in Better Endings. These questions helped us to investigate – together and with our different perspectives – some much more nuanced understandings of our current system, and explore ideas for working differently to radically enhance people's experiences at the end of life.

POWER

Who is 'allowed' to care for the dying? Who 'knows' best?

Who owns and defines the space where end of life care happens?

How are inequalities of power played out at end of life?

How do we help those with power to share their power?

CAPABILITY & EXPERTISE

Who has the skills and knowledge to care for the dying?

How can different skills and perspectives be integrated?

What capabilities are we missing?

Where are the capabilities that we are currently not seeing or not fully utilising?

PAIN & DISCOMFORT

What needs to happen for physical symptoms to be managed in more places and by more people?

How might we acknowledge and respond to emotional pain as well as physical pain?

How do we understand what frightens people the most and what their preferences might be?

How do we deal with long-term suffering, frailty and less predictable illnesses?

MEANING

Who defines the meaning of end of life? Who defines what is important and 'what matters' to us at the end?

In what ways (both explicit and implicit) is the meaning of end of life defined?

Where are the opportunities for exploring meaning and sharing meaning?

RISK & UNCERTAINTY

How do we deal with the fact that end of life is unpredictable?

How do we deal with the increasing unpredictability of the way we die?

Who or what determines how we approach risk?

What information, experience and judgements are necessary to navigate risks at end of life?

COLLECTIVE GROWTH

What are the opportunities in care of the dying that allow individuals to grow and learn?

How might a sense of our own mortality and experiences of caring become a universal point of connection between people and communities?

How can the 500,000 people who die every year in Britain help the rest of us learn what is important about being human in the world today?

Acknowledgements

We are grateful to the people who shared their personal stories in this publication, and through the wider research that has been part of Better Endings. Special thanks are also due to Sonia Kneepkens for her research leadership and storytelling (with pictures and words).

Adebola is always interested in hearing from potential volunteers and supporters of her hot meal services (which operate in several locations across Southwark). Email Adebola24@yahoo.com.



ABOUT INNOVATION UNIT

Innovation Unit is a not for profit social enterprise. We create new solutions that enable more people to belong and contribute to thriving societies. We develop alliances for change with places, organisations and systems, to ensure that innovation has lasting impact at scale.



ABOUT GUY'S & ST THOMAS' CHARITY

Guy's and St Thomas' Charity is an independent, place-based foundation. It works with Guy's and St Thomas' NHS Foundation Trust and others to improve the health of people in the London boroughs of Lambeth and Southwark, and to tackle the major health challenges affecting people living in urban, diverse and deprived areas.

Better Endings

Creating new solutions for
end of life care and support.

 **Innovation
Unit**
New solutions
for thriving societies

