



# STORIES OF ORDINARY PEOPLE OPPOSED TO ASSISTED SUICIDE

LIVES WORTH LIVING

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# FOREWORD



Hardly a week goes by but we read about another celebrity calling for a change in the law to allow elderly, disabled and sick people to be helped to kill themselves. The people in this booklet are not celebrities. They are ordinary people who, for a variety of reasons, are deeply opposed to assisted suicide. In these pages you will read first-hand accounts of the real fears and worries which a change in the law would bring.

Living with a severe disability is not easy. Caring for a family member with a disability is challenging. Opposing assisted suicide as a medical profession can be difficult and lonely. But life still brings joys. This shines out of the stories here. You will see smiling faces throughout this booklet. These smiles are genuine.

Reading these stories, I felt that each person became my friend and I gained many different insights into why assisted suicide is so wrong. I shall quote from these stories when I write to the politicians who represent me in Parliament. Please share these stories with others.

I want to thank the ten people who appear in this booklet for their willingness to speak out and their beautiful witness to life.

A handwritten signature in black ink that reads "John Deighan". The signature is written in a cursive, flowing style.

JOHN DEIGHAN  
*Chief Executive of SPUC*

*September 2024*

*'I wouldn't want my family to be left with any guilt or trauma caused by my decision to leave them, rather than waiting for a natural end.'*

PATRICIA

*'Helping people to kill themselves has no place in the holistic, sensitive care I have been trained to give.'*

MARY ANN

*'What a terrible tragedy to let a doctor help you to kill yourself based on mood and feelings.'*

HARRIET

*'We've seen state-sanctioned eugenic killings before. We'll be seeing it again with assisted suicide.'*

TONY

*"How long will it be before assisted suicide becomes normalised?"*

FR ANDREW

*'I am fighting for my mam every step of the way.'*

TERRY

*'Elijah could easily be seen as an inconvenience and a cost.'*

REBECCA

*'Mark's life is peaceful and dignified.'*

EPPIE

*'I hadn't thought I could love him more tenderly but found that I could.'*

PETER & PATRICIA

*'Doctors are taught to save lives. If the law is changed we would be saying to them: "We also kill people to end their suffering."'*

DR DOMINIC WHITEHOUSE

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# INTRODUCTION

Assisted suicide, also known as assisted dying, can be debated from many perspectives; individual autonomy, dignity, safety, disability rights, protection of the vulnerable.

However, statistics and arguments will only go so far. The threat of a change in the law to make assisted suicide legal, is deeply disturbing to vulnerable people and their families. We must listen to their voices.

In this booklet we share ten stories of ordinary people for whom legalising assisted suicide is a dangerous and frightening prospect. These are people grappling with what a change in the law would mean for them, their families or their profession.

Any one of us could find ourselves facing the sort of issues recounted by the people in this booklet. These stories are for us to share with others, in particular with politicians whose vote will determine whether the law on assisted suicide is changed or not.

## ASSISTED DYING OR ASSISTED SUICIDE?

In this booklet, we use the term 'assisted suicide' throughout. 'Assisted suicide' is also known as 'physician-assisted suicide'.

The term 'assisted dying' is often used to cover both assisted suicide and euthanasia in countries like Belgium and the Netherlands where both are permitted. In the UK, the term is generally preferred by its proponents to assisted suicide and euthanasia, but it has no meaning in law.

A 2022 Parliamentary briefing gives this definition of assisted dying:

*'Assisted dying' refers here to the involvement of healthcare professionals in the provision of lethal drugs intended to end a patient's life at their voluntary request, subject to eligibility criteria and safeguards. It includes healthcare professionals prescribing lethal drugs for the patient to self-administer ('physician-assisted suicide') and healthcare professionals administering lethal drugs ('euthanasia').*

All proposals in UK parliaments have so far been for assisted suicide, not euthanasia.



## PATRICIA'S STORY

Patricia (61) was diagnosed with MND (Motor Neurone Disease) in 2023, with the onset of symptoms in 2021. The average life expectancy for MND is 2-5 years. So far, the disease seems to be making slow progress in Patricia, but she is deteriorating. Her legs don't work, and she has significant abdominal weakness. Her breathing is increasingly compromised, and her voice is cracking.

This is a difficult and relentless disease and Patricia's husband is juggling full time work as well as being her main carer. Life may be shortened for Patricia, but she wants to live it to its natural end. She is opposed to any change in the law which would allow assisted suicide.

### **WILLINGNESS TO CARE**

'It's a lot of work for my husband', says Patricia from her home in London. 'But I see his love for me in his willingness to care for me, despite the hardship. For me, a law helping people to kill themselves because they are ill or old indicates a utilitarian mindset, implying that if you're not useful you shouldn't be alive.'

What disturbs Patricia most is that a change in the law would be open to coercion, intimidation, and mandates, leading people to think they have a duty to kill themselves.

She says: 'Illness is part of being human. It's the sign of a civilised society that people who are vulnerable, elderly and disabled are looked after. It concerns me that it would come to be seen as irresponsible, wanting to stay alive, while becoming more and more dependent.'

Patricia says that, at each moment of loss, she does grieve for the things she can no longer do. A designer by profession, she loved sewing and for many years ran craft sessions at a youth club for girls but now enjoys sharing her skills by giving advice via WhatsApp. She loves flowers and often created arrangements for weddings. Now she has asked friends to stop bringing her flowers because she can't see to them herself and doesn't want to give her husband yet another task.

## PLUMBING THE DEPTHS OF LOVE

For Patricia and her husband, illness is above all a lesson in love. 'As a couple, we are plumbing the depths of love', she says. 'Every day I think I'm so glad I married him.'

'Caring for someone is only a burden if you don't want to do it, or you feel you can't give as much as is needed,' says Patricia. 'Getting outside help eases the load and means family members can support each other and benefit from this special time. Family dynamics change when something like this happens. It can become a time of bonding.'

Patricia is clear that she is not chaining anyone to her. She is not putting any pressure on her children.

## ASTOUNDED BY GENEROSITY

'Human beings much prefer being in control and, paradoxically, feel good when they give to others', explains Patricia. 'I have been astounded by the generosity of people I didn't have close ties with who have volunteered help, and new friendships have blossomed. Now I'm weak and dependent on others, I've had to learn to live in this vulnerable state and be the receiver. People give what they can, I don't judge anyone by how much they help me. I hope it is making me more grateful.'

What is Patricia's response to those who say that the right to end your own life when it becomes unbearable is a humane and caring solution?

## FRIGHTENING ASPECTS OF THE DISEASE

'I know what may be ahead of me with MND', says Patricia. 'There are some very frightening aspects of this disease. And, yes, life is overwhelming on some days. We're only just coping at the moment. I'd rather not be in this state. Physical deterioration isn't pleasant, and this is not how I'd like to be seen. But offering to help me kill myself is not an act of love. Palliative care is there to help make my symptoms bearable and to help me at the end. 'I didn't determine when I was born, and I don't think I have the right to end my life. I wouldn't want my family to be left with any guilt or trauma caused by my decision to leave them, rather than waiting for a natural end. We need proper closure, and I don't think my family would get that if I chose to kill myself.'

'Times of suffering can push us to our limits, tempting us to lose hope. Support from others can help us in times of weakness. If legalised killing became law, these times of vulnerability could be exploited, opening the door to euthanasia. People could be persuaded to kill themselves for any number of reasons.'

## LITTLE THINGS ARE IMPORTANT

'Little things are important', says Patricia. 'I love the view from my window. Human touch is so important. Stroking someone's hand can help a lot. We need training in kindness and love.'

'The greatness of the human spirit is that we can endure great hardships. That's how we grow and become more human, more compassionate. I am in awe at the dynamism and vitality of other people in my online support group, who are full of life and generosity.'

'I still have a lot to offer. I may not be around to play with any grandchildren, but I can support my children and encourage them to meet life's challenges. If assisted suicide was on offer, people may give up rather than overcome difficulties.'

Patricia's view is that, however small her world becomes, she wants to be alive in it.







## EVERY DAY IS A LITTLE LIFE

Mary Ann works in a nursing home in Surrey and is vehemently opposed to a change in the law to legalise assisted suicide.

'My work is caring for people who have lived a life which is now coming to an end. Each one is coming to terms with this in their own way. But we always want to make these last days as positive and as happy as possible', says Mary Ann. 'Where I work, we say, "every day is a little life", and that's our focus. If assisted suicide was an option, this positive focus would change.'

Mary Ann qualified as a general nurse in 1979 at St Thomas' Hospital in London. She then went on to train as a midwife. Later on in her career she turned to elderly care and has worked for over twenty years in nursing homes. Now she works part time.

### A REWARD FOR ME

'We take people when they can no longer be cared for at home. The nursing home is another home. People come with their own, familiar belongings. There are no restrictions on visiting', says Mary Ann. 'My role is to do all the work which then leaves families free to enjoy the last months or days of their relative's life. A reward for me is seeing a man sitting quietly, holding his wife's hand. Or someone enjoying a meal.'

Anyone who is dying is accepted at the nursing home where Mary Ann works. Her work involves enabling a good death for each person by controlling symptoms such as pain, sickness and breathlessness.



'We don't withhold medication. This can sometimes create the double effect that death may come more quickly. But we are careful to help patients keep a clear mind', says Mary Ann. 'If we need more expert advice, or we feel we are not managing a patient as well as we could, we call in a specialist palliative care nurse.'

### ZEST FOR LIFE

Mary Ann sees the zest for life people can have even when death is close. 'I remember one man who was so proud and pleased that he had lived beyond the three months he was told he had left. He was happy to be alive. Then during a doctor's appointment, he was told exactly how ill he was. After that, he seemed to give up. He stopped eating and drinking and died shortly afterwards. The physical and emotional are closely linked.'

It was Dame Cicely Saunders (1918-2005) who made the link between physical and emotional pain. She pioneered the modern hospice movement where pain and symptom control were to be combined with compassionate care.

'England is a world leader in care for the dying thanks to Cicely Saunders', says Mary Ann. 'If assisted suicide is legalised, caring and killing would both be happening in nursing homes. It is a travesty to conflate the two. Helping people to kill themselves has no place in the holistic, sensitive care I have been trained to give.'

### EMOTIONAL NEEDS

Mary Ann is alive to the emotional needs of those she cares for and their families. 'There can be huge family issues to resolve at the end of life. Conflict between siblings is very hard. I try to support and help families. This is part of helping my patients. Assisted suicide would take away the opportunity for families to find closure.'

'I try to look after the spiritual needs of my patients too. Sometimes the offer of a visit from a priest is rejected. One patient said that the last time she was in a church was the funeral of her son who committed suicide. She couldn't move beyond that. She was constantly asking for painkillers when we knew she didn't need them. Her pain was spiritual, not physical.'

### BRINGING CALM AND ACCEPTANCE

In the course of her work Mary Ann shares intimate moments with families when a patient is very near death. She tries to bring calm and acceptance to a distressing time. 'Once I was with a patient right at the end. Her daughter and son-in-law were in the room and were very upset. The daughter told me that her mother had been baptised a Catholic, so I asked if it would help if I said a prayer. They said yes. I knelt down and began to say the Our Father. Suddenly the daughter said, "Look, mum is making the sign of the cross." The lady died shortly afterwards. Hopefully that brought some peace to them all.'

For Mary Ann, looking after people at the end of life is so much more than controlling symptoms and alleviating pain. Yet this is the lens through which advocates of assisted suicide see death. The solution to pain and difficulty is to choose death.

'Sadly, some people in my profession are starting to agree with it', says Mary Ann.

Yet, if assisted suicide is legalised the great danger is that the million little details of care, compassion and love which nurses like Mary Ann give their patients would disappear. It would take the heart out of making every day a little life for their patients.



# LIVES FILLED WITH LOVE

'As a child I was fascinated watching my beloved grandfather', says Harriet. 'While he was sitting down his legs would begin to dance. Getting ready to enjoy a glass of whisky I saw him begin with a few rocking movements to place a glass into his rather shaky hands. Then, after an "around the world" movement, he succeeded in bringing this little tippie up to his mouth for a sip.'

To the outside world, Harriet says that her grandfather looked like 'a romantic drunk'. In fact, he had Huntington's disease. But, says Harriet, 'he always masked it with a wonky wink and slightly wobbly kiss on the hand for the ladies'.

Huntington's disease affects motor skills, so it can be difficult for people to talk, swallow and walk. It also affects mood, and can cause severe depression. It eventually kills the person, and Harriet's grandfather died of this disease.

Harriet grew up knowing the disease was in her family. Seeing how her grandmother looked after her grandfather made a deep impression on her: 'She looked after my

grandfather so well. She prepared beautiful finger food which he could manage. He was so incredibly valued, and he knew it.'

## THEY DON'T WANT TO DIE

At 21, Harriet decided to take the test. With marriage on the horizon, she felt that any future husband should know what he was marrying into. Her test came back positive. In the event, the man she married 'took me for what I was and loved me as I was'.

Today, Harriet, her husband, their eight children and two goats live in rural Norfolk.

Harriet is extremely worried at the prospect of a change in the law to allow assisted suicide. 'Two of my aunts have the condition. I watch them live so bravely and courageously with this terrible illness. They don't want to die, and they don't want someone to make that decision for them.'

'If the law changes, it could happen that one day when my aunties' mood is affected by the condition, they might think of ending their lives legally', says Harriet. 'A temporary desire to end things could be validated by people around them.'

'A day later, their mood may have gone full circle, and they would think perhaps that things aren't so bad after all. What a terrible tragedy to make a decision to let a doctor help you kill yourself legally, based on mood and feelings.'

### **NUMEROUS CONFRONTATIONS**

As a carrier of the disease, Harriet knows only too well how the lives of people with Huntington's are devalued. 'And that's without an assisted suicide law!' she says.

Harriet has had numerous confrontations with the medical profession. When she became pregnant with her third child she was asked if she wanted a test to find out if the baby had Huntington's disease. Harriet was not prepared to risk her child's life by having an invasive test, the only purpose of which was to abort the baby. 'I instantly fought back at this poor doctor, who obviously hadn't anticipated my reaction', recalls Harriet. 'I told her that what she said not only lessened the value of my unborn child's life but also deemed my life less valuable too!' Harriet had a similar conversation with each pregnancy.

### **NOT EASY TO MANAGE**

Both Harriet and her husband decided early on that they would not test any of their children. If as adults their children decided to take the test, that would be their prerogative to do so.

'We wouldn't want our children to feel in any way stressed or depressed by being tested early', says Harriet. 'There may also be an issue of guilt as some may have it and some may not. This is not something easy for children to manage. We don't think they need to have their childhood blighted by such a subject.'

'Probably the most important reason why we do not agree with testing our children is because this could actually save their life', says Harriet. 'During the teenage years, knowing they have the gene could start to affect their mental health. If they have the gene, they could start thinking there is no point in living, as their lives are seen as worthless. It could seriously affect their self-esteem.'



'There is also the horrific thought that if they knew assisted suicide was available and legal, they could think of this as an option. Thank God that this message wasn't around when I was growing up, otherwise my mental state might be different.'

### **THEY DESERVE TO LIVE**

Harriet's family is a powerful witness to the way in which living with a cruel disease can be meaningful, purposeful and filled with love. 'My grandfather had a very British attitude of getting on with life and staying cheerful. And he was always deeply loved.'

'Today my aunties are hugely loved by all my children, their other nieces and nephews, and by their brother and sisters who go to see them every week. They deserve to live without doctors agreeing, or suggesting, that they should be "helped" to die. I think it would be tragic if their right to life were taken away from them. We could get to the point where we can't trust our doctors.'

'Life is life', says Harriet. 'No matter how big or small, no matter how young or old, no matter how happy or sad, no matter how rich or poor, no matter how hard or easy, no matter how sick or well. It is worth living and must be protected.'

# THE BRAVEST MAN I EVER MET

Tony's brother Stephen was 35 years old when he died of a brain tumour in 1991. 'He was the bravest man I ever met', says Tony, who lives in Glasgow. The memories of his brother's illness and death highlight for Tony the ways in which a change in the law to allow assisted suicide would be dangerous and wrong.

After the initial diagnosis, Stephen had surgery to remove the tumour, which was a success. In fact, the surgeon was delighted. However, a failure in the system meant that Stephen did not receive radiotherapy. As a result of not getting the full treatment he needed, Stephen developed a secondary tumour. For the last three months of his life he was paralysed from the neck down.

## NEVER FELT SORRY FOR HIMSELF

By that stage, Stephen would have fitted the bill for assisted suicide under current proposals; he had fewer than six months and many would consider that he was enduring unbearable suffering. Yet Tony remembers that Stephen never once asked for his life to be ended. 'Stephen never felt sorry for himself. He never complained', says Tony.

Tony pays a high tribute to the Marie Curie hospice in Glasgow which cared for Stephen during his last months. 'Palliative care gave my brother time to be with his wife, my mum and dad, other relatives and his friends', says Tony.





Is Tony worried that bringing in assisted suicide will have a negative impact on palliative care? 'Very much so', he says. 'Stephen received the best possible care. There is not enough funding for hospices as it is, there could be even less if assisted suicide comes in.'

### **NOT A BURDEN**

Helping sick and vulnerable people to kill themselves is a dangerous road to go down, in Tony's view. Assisted suicide would make sick and elderly people feel they are a burden to their family. Was Stephen ever a burden?

'Not at all', says Tony. 'We love each other as a family. Stephen didn't feel he was a burden, and neither did we. The burden we carried was not having him with us after he died.'

If assisted suicide had been legal 33 years ago, it might have been harder for Tony's family. As it was, Stephen had a natural and peaceful death without his family feeling the pressure that assisted suicide could have been an option.

### **WE'RE CARING LESS**

Reflecting on the experience of his brother's death, Tony is concerned that assisted suicide would deprive other families of the extra time palliative care gave to Stephen. 'Stephen wanted to live however much life was left to him', says Tony. 'Helping people to die is just not right. We hear now of people with Alzheimer's and dementia being killed by euthanasia. Is that where we're going? We're meant to be a caring society, but we're caring less.'

'We haven't learned the lessons from the past', says Tony. 'We fought a war to stop eugenic policies and euthanising the most vulnerable members of society. We've seen state-sanctioned eugenic killings before. We'll be seeing that again with assisted suicide. If this was wrong 80 years ago, why is it right now?'



## WHEN LOVE IS MOST NEEDED

14 May 2023 started as a normal day for Peter (74) and Patricia, who live in Middlesex. Peter is a retired civil servant and Patricia is a freelance tutor. At 6pm Peter wished one of Patricia's students 'Good luck' for an exam the following day. Half an hour later Peter had a haemorrhagic stroke and life changed dramatically forever.

Peter's health had been deteriorating since 1991 when he developed epilepsy, followed by arthritis and hearing loss. 'But the stroke was a huge shock', says Patricia. 'I rang my daughter who was on her way over with my grandson. She phoned for an ambulance and Peter was in Charing Cross Hospital in central London for the next three weeks. Complications arose and several times we were informed that we might be near the end.'

### TOUCH AND GO

Peter was then transferred to West Middlesex Hospital. 'Fortunately, Peter was entrusted to a professor whose approach is to give stroke patients time, rather than assuming they will not make it', says Patricia. 'For many weeks it was touch and go, but this approach proved right. Peter came home on 14 August.'

'We are blessed to have Peter at home, but every day is very challenging and looking after his needs is time-consuming', says Patricia. Peter is completely bed and chair bound, being paralysed on his right side. At night he is on a catheter, and he has to use incontinence pads day and night. Carers come four times a day to wash and change him and to administer medication.

## THE VALUE OF EVERY LIFE

Peter and Patricia have always believed in the value of every human life. Their two daughters were adopted from China. Eloise is a highly skilled children's nurse and Christina a talented young designer.

'A turning point in Peter's recovery came last June', Patricia recalls. 'I told Peter that Christina was being invited to prestigious interviews following her graduate show. As I said, "Our little girl!", he squeezed my hand and smiled, and we remembered the one-year-old we adopted in Guangzhou and how her artistic talent had emerged at an early age.'

Both Peter and Patricia are opposed to assisted suicide. 'The time for people to die is when it is the right time for them to go, not when they or anyone else decides,' says Patricia. 'What terrifies me about assisted suicide is that no human being is omniscient, and doctors should never believe that they are, no matter their skill and experience. We just don't know how long someone has to live.'

'Today, Peter is very much living, delighting in his new grandchild. He is still very interested in current affairs, and I read articles to him. His speech is clearer every day and, ironically, his hearing, which was becoming a real problem before the stroke, seems improved, possibly because he is aware he has to concentrate more.'

## SHOCK AND CONFRONTATION

Patricia is candid about the huge impact of an event like her husband's stroke which puts both the patients and their loved ones in an extremely vulnerable situation 'There is the shock and there is the confrontation with medical staff who all seem to talk a different language.'

'Several doctors seemed genuinely surprised that we did not immediately say that Peter would prefer not to live a disabled life', Patricia remembers. 'Peter was fragile, but so were we. We were so fortunate that Eloise understood all the technical terms and jargon, questioned and challenged staff and was then able to explain to us what was happening. But how many families have that privilege?'

Patricia is also concerned that, if the law is changed, remarks made by a patient could be interpreted as a wish for assisted suicide. 'In the early days of Peter being at home, one afternoon he said to me, "This isn't living", as he sat waiting to be changed, unable to do anything for himself. But I knew that he was thinking about how he could carry on, and not should he carry on. I told him that he had come so far since the stroke and that we loved him very much.'

If assisted suicide was legal and inevitably became part of the system, Patricia worries that other families facing a similar situation would be at risk. How many very sick people and their family will properly understand what is being said, if assisted suicide is suggested, and what the implications are? Less articulate people could well end up saying something they do not fully mean. If their first language is not English, no matter how fluent the speaker, the strain of caring for a sick relative could cause incomprehension.

## SMALL PRECIOUS MOMENTS

Peter is part of a loving family. His three-year-old grandson insists on being 'the doctor' when he comes to visit, helping Patricia to fill syringes for supplementary liquid. Peter loves to hear his grandson talking about visits to the park. Small, precious family moments such as these make Peter's life positive.

There have been many times in the 42 years of their marriage when Patricia has lived the gamut of the vows she and Peter made to each other, 'for better, for worse, in sickness and in health'.

'When Peter became epileptic aged 41, I hadn't thought I could love him more tenderly but found that I could', says Patricia. 'Last year, when we thought he was about to die, for weeks I was saying a line from a poem by Elizabeth Barrett Browning: "I shall but love thee better after death".'

'Peter is fantastic', says Patricia. 'He has surprised us all.'

Peter and Patricia show us why assisted suicide is so wrong. It will kill the most vulnerable people, and it will kill real love at the time it is most needed.





# CROSSING A DANGEROUS LINE

'If there's a change in the law to allow assisted suicide, we'll be crossing a line', says Fr Andrew Bishop, priest in charge at Croydon Minster in the London Borough of Croydon. He feels strongly that a change in the law would be a statement that human life is expendable and that some lives are not worth living. 'This will affect us all', he says. 'I think of the words of John Donne: "Any man's death diminishes me, because I am involved in mankind".'

'Not accepting assisted suicide is somehow taken to mean that you are not caring', says Fr Andrew. 'People assume that caring for the dying is always about the alleviation of pain. Assisted suicide risks reducing care for the dying to only that. This view impoverishes our status as human beings.'

## ISOLATION

Ordained into the Church of England in 1996, Fr Andrew has seen people becoming increasingly isolated over the years of his ministry. 'People still want to be part of a community, and yet at the same time they want to be more and more individual', says Fr Andrew. 'The language of autonomy around assisted dying undermines our solidarity with others. We don't decide when we are born and when we die should not be our personal decision. My fear is that because frail people will be put under pressure to choose to end their own life, that choice could become a heavy burden, isolating them when they most need to be understood.'

An aging population combined with fragmented families will also lead to problems in Fr Andrew's view. 'In families involving multiple sets of children, where does the decision-making around assisted suicide really lie? Who gets listened to? Amid the potential tension and disharmony among loosely connected family members, the dying person could get caught in the middle.'

## DISTINCTION WITH ANIMALS

Fr Andrew, who is married with four children, grew up in a household where his father was a vet and his mother a geriatric nurse. 'I was definitely aware of the distinction between caring for animals and caring for humans. Humans share some creaturely aspects with animals, and I saw the sympathetic way in which my father put down cats and dogs. I also knew that the loving care my mother gave her patients was different.'

## SLIPPERY SLOPE

There is no doubt in Fr Andrew's mind that legalising assisted suicide will put us at the top of a slippery slope. 'It will be a slope and it will be slippery', he says. 'How long will it be before assisted suicide becomes normalised? Could we see a time when, as has happened with abortion, assisted suicide moves away from doctors and into the hands of organisations who will send pills through the post for people to kill themselves?'

Another pressing question is how safe will safeguards actually be in an assisted suicide law. 'Doctors have difficulty controlling the use of antibiotics. The pressure on doctors to approve requests for assisted suicide could be intolerable. Soldiers come back from war traumatised by participating in the act of killing. We need to wonder what this will do to members of the medical profession.'

## AN UNHAPPY LEGACY

Ministering to families who have lost someone to suicide is part of a priest's role. 'Suicide is complex. And it's always an appalling shock for families when a tragedy like this happens', says Fr Andrew. 'There are also the unanswered questions which remain with the family. Assisted suicide is planned and expected, but there could be an



unhappy legacy of doubt and misgivings among those who encouraged and supported the dying person to take his or her own life. Ultimately there is still the reality of what the act of suicide actually is.'

The church must up its game on promoting good end of life care and demystifying death, according to Fr Andrew. 'The church needs to speak more confidently about the end of life. I see funerals becoming more secularised, reduced to a celebration of life. The focus of commending the person to God as one of His children is lost. Death is not a defeat. The Easter celebration tells us that victory over death has been won.'

'Assisted suicide may appear to be a loving option. But the truly loving way is to accompany the dying person to the natural end of life, even if it's hard.'

# A PEACE SHATTERED

Terry has always been opposed to assisted suicide. He is passionate about protecting the weakest members of our society both before birth and at the end of life. But when his mum Julie (66) became seriously ill in January 2024, Terry became even more fearful about a change in the law to allow assisted suicide.

'I am experiencing at first-hand what it's like when a person is really sick in a health service which is overwhelmed and bursting at the seams', says Terry. 'Individual doctors and nurses have been great, but the system is on its knees. Just recently my mam was admitted to hospital and told she would need to be in for a week. Two days later she was discharged at such great speed she arrived home with a cannula tube still in her arm. Offering assisted suicide could become the easier option.'

## A HANDS ON GRANDMA

Julie, who lives near Terry in Middlesbrough, was very active until she became ill. Up until two years ago she was working as a food technology teacher in a local secondary school. Since then, she has been a hands-on grandma to her nine grandchildren who live locally.

'Mam was round at our house every evening helping with the children', says Terry. 'She was always helping someone. Before she became ill, she was a volunteer at the local food bank.'

Julie already had type 2 diabetes, and a couple of years ago she was diagnosed with non-alcoholic cirrhosis of the liver. Since February 2024, she has suffered repeated infections, which have been treated. But despite several hospital admissions the cause of her illness has not been found. There is also the constant worry of liver failure.





### DOCTORS SEEM FRUSTRATED

Terry's experience with his mother has highlighted for him that care is reactive rather than proactive. Symptoms are dealt with, but there's little drive to find out the cause of Julie's illness.

'There's a reluctance to investigate what is causing my mam to be so unwell. It seems as though it's less expensive and less hassle not to repeat scans and tests', says Terry. 'Some of the doctors seem as frustrated as we are about this. They are caught up in a system that seems very poorly managed.'

Since she became ill, Julie has lost a lot of weight, and her mobility is compromised. 'I feel like I am fighting for my mam every step of the way', says Terry. 'What would happen to someone in her condition who had no family to advocate for her? These situations would leave some people very vulnerable to assisted suicide. It's terrifying really.'

### A JOY AND A PRIVILEGE

Faith and family have always been at the heart of Julie's life. 'We are a close family', says Terry. 'We go in and out of each other's houses. No one rings the doorbell.'

Terry can see that his mother's quality of life has diminished greatly. 'This is a very challenging time for my mam and for our family; there's no doubt about it', says Terry. 'But caring for mam is not a burden for us. And my mam doesn't think of herself as a burden. She stays optimistic. She's always been a glass half full person.'

For Terry, caring for his mother is a duty. But it's also much more than that. 'Actually, caring for a very sick person is a joy and a privilege', he says.

Thinking about what it would be like if assisted suicide was a legal option, Terry worries that this could lead to family division. 'There could easily be situations where some family members think that assisted suicide would be the way to go when a relative is very sick.'

Terry knows that his mother would never consent to assisted dying. But his ongoing battle with the health care system on her behalf, highlights how vulnerable sick people are. These conditions would help make assisted suicide acceptable.

### FUNDAMENTALLY UNNATURAL

Terry can see how pressure to choose assisted suicide could lead people to do something which is fundamentally unnatural.

'The emotional fall-out for families where a very sick relative is helped to kill themselves would be profound' says Terry. 'How could you let the person who brought you into this world kill herself? The impact of that would stay with you until your dying day.'

Terry is leaving no stone unturned to help his mother. Whatever the difficulties, his heart is at peace. If assisted suicide is legalised, that peace would be shattered.



# ONE OF SIX

Four-year-old Eliah is one of six. That's the way her mum, Rebecca, sees her: 'She's one of our six children and she's a blessing, like all of them.'

Rebecca, who lives in Northampton, is a busy stay-at-home mum. She describes her pregnancy with Eliah as 'unremarkable', but she says that early on she felt there was something different about her fourth daughter.

At two months Eliah started having seizures. She was given medication to control this, and then she was tested to find out the cause. 'They did chromosomal testing', says Rebecca. 'But they didn't tell us anything at the time.'

At eight months, Eliah turned mottled blue and started vomiting. She was taken into hospital, and she was found to have an enlarged heart. During surgery baby Eliah's heart arrested and she was given chest compressions to bring her round. 'She made it through the surgery and was in intensive care for six weeks', says Rebecca. 'After that, every day counted, and it felt like a miracle when she reached her first birthday.'

## COMING A LONG WAY

Eventually, medical detective work revealed that Eliah has 1p36 deletion syndrome, which occurs when a piece of genetic material is missing. Eliah is unable to walk or speak and she is currently fed by a nasogastric tube. Her development is different from other children, but having just turned four, Eliah has come a long way. She has been weaned off several of her cardiac medications and now only needs one, and she no longer has epilepsy. Her parents take a positive view of her uncertain future.

'If you looked at Eliah's life on paper, it could seem like the end of the world', says Rebecca. 'But in real life it's not like that. Eliah plays with her toys, loves watching "Bluey" and can be a cheeky little girl.'

So why does the thought of assisted suicide worry Rebecca? 'I am really concerned about how assisted suicide will make disabled people even more vulnerable. It terrifies me that people will think that Eliah's life is a burden to society.'

Rebecca firmly believes in the right to life of unborn children. 'During my pregnancies whenever I was asked to go for a screening blood test, I just said no thank you. Screening is so routine. They can't pick up Eliah's condition before birth, but if they could and I had been tested, I would have been asked if I wanted an abortion.'

## QUALITY OF LIFE

'People aren't used to seeing disabled children', says Rebecca. 'When I'm out with Eliah, some people look at her with pity, particularly as she has a tube in her nose. Others look at her with disgust. To them it looks a bleak picture and that my daughter has no quality of life. I worry that people will judge Eliah's life, especially when she is older. How dare anyone judge someone else's life?'

Children have a different response to Eliah. 'Other children are curious about her', says Rebecca. 'They love playing with her when I take her to the park.'

'Her older sisters love her. They are like mini mums. They can soothe Eliah when she gets upset. And they are in awe when they see Eliah doing something new. It's: "Mum, look what she's done!"'

Like many parents of disabled children, Rebecca and her husband worry about Eliah's future. 'I can't bear to think of a time when I am not there to advocate for her', says Rebecca.

## AN INCONVENIENCE AND A COST

Rebecca thinks that assisted suicide will affect attitudes and behaviour very quickly. 'We've seen how the law on smoking changed behaviour. You never see anyone smoking in a supermarket café. Assisted suicide will soon become normal. Eliah could easily be seen as an inconvenience and a cost.'

Eliah very nearly died when she was a baby and needed extensive interventions from specialist intensive care doctors, nurses and paramedics.

'Eliah was clinically unstable for some time,' recalls Rebecca. 'But doctors gave her every chance they could. Yet years down the line, if Eliah gets poorly, the decision could be made to end her life. Her life could be considered unworthy of care and medical attention. This seems to be such a contradiction; to give up on her when such efforts were made to save her when she was a baby.'

## NEGATIVE REACTIONS

Rebecca had to deal with negative reactions when she became pregnant with her last child. 'Some people were saying: "Aren't you worried?" We weren't worried because we knew that Eliah had not inherited 1p36, it was just a random occurrence. It could happen again, but we wanted another baby, and now Eliah has a great buddy.'

Rebecca and her husband recently visited a school for children with profound needs. 'I was worried about Eliah going to school, because she wouldn't be able to tell us if she was unhappy there. But we were overwhelmed at how amazing the school was. We were crying when we saw what the children were doing and the wonderful way the staff worked with them. I am now happy about Eliah going to school. She'll be like her older sisters, with her own friends.'

## THE POSITIVE SIDE

Rebecca is passionate about showing the positive side to having a child with special needs in the family. She is bringing up Eliah the same as her other children. Eliah sits at the table with the rest of the family at mealtimes, she goes out everywhere with the family. 'She's thriving being part of a family where she's loved. We celebrate every small milestone Eliah reaches. I want other parents to see that having a disabled child is not all doom and gloom. It's the exact opposite.'

While Eliah is cherished within her family, she is an obvious target in the culture of death. She made it into the world at birth, but, as Rebecca says, assisted suicide is 'another threat looming'. 'Eliah is relying on us to speak up for her life', says Rebecca. 'And now's the time.'



## SHARING OUR JOYS

Dr Mark Blackwell worked as a psychiatrist for 28 years. In 2011, he was diagnosed with Parkinson's disease. In 2016, he underwent deep brain stimulation surgery, to help with the symptoms. Unfortunately, after the operation, he had a brain haemorrhage resulting in a severe stroke. The left side of his body was paralysed.

It is difficult for Mark to speak, but he is still able to communicate. He says: 'At one stage, I wanted to die. The thought of 30 years of this sort of life was awful. Not able to tell people what I wanted to say, because my speech is impaired.

'But I want to be alive because important things have not changed. Eppie, my wife, loves me; my children love me. I have ten grandchildren. I love having my friends and family around me.'

### NOT ALL MISERY

Eppie wants people to know that life with a severe disability is not all misery.

'Of course, our life has changed since Mark became ill', she says. 'But Mark and I enjoy our life really very much as it is now. Our children and our friends would really miss the love and presence of Mark if he ended his life.'

Dr Blackwell is at the heart of his family. Since his illness, his youngest daughter has graduated from university and one of his sons achieved a doctorate in Medicine – important moments he has been able to share with them, along with seeing the arrival of his grandchildren.

During the pandemic his fifth child got married to a beautiful and loving lady. Another son is getting married next year. Mark has also seen the successes of his sons-in-law. One has graduated from Harvard Business School, and another has qualified as a GP.

### HOPE AND OPTIMISM

'All these events bring joy and consolation to Mark in spite of his debilitating illness', says Eppie. 'As a family, we endeavour to face the challenges of life and the

difficulties that Mark's illness brings with hope and optimism. My family has become even more united, each one in their own way contributing to Mark's wellbeing.'

Mark says: 'I am happy to be alive. If assisted dying is legalised, it would make me feel that my life and my suffering are a waste of time. It would make me feel I am a burden for Eppie and my children. I would lose respect for myself.

'I am lucky. I have Eppie and my children to protect me. But I worry about what would happen to other people if the law is changed.'

And Eppie says: 'Despite his dependence on others for his many needs, Mark's life is peaceful and dignified. We are definitely very thankful that Mark is with us. We are so happy that he has chosen to live and let us share our joys with him.'





# THE PRIVILEGE OF CARING FOR MY DYING PATIENTS

Dr Dominic Whitehouse is a palliative care consultant. The greatest privilege of his work is becoming close to his dying patients and their families. 'Dying is a difficult but beautiful time', he says. 'And we can make a great difference to any suffering that people may be undergoing.'

Dr Whitehouse came to palliative care later in his medical career. When his local hospice in Sussex was unable to recruit a consultant, due to one retiring, and was at risk of closure, Dr Whitehouse stepped up and took a two-year part time diploma to qualify for the position. 'It was the best move I ever made!' he says.

The word 'palliative' comes from the Latin word 'pallium', which means to cloak. 'We cloak the difficult physical, spiritual and psychological symptoms which get in the way of a peaceful death', explains Dr Whitehouse. 'This can be

done by careful use of medications. But just as important is recognising the dignity of the patient, befriending them and finding out what is important to them. We become expert at helping our patients in all these areas.'

## 'I WOULD BE DEVASTATED'

Asked how he would feel if there was a change in the law to allow assisted suicide, Dr Whitehouse replies: 'I would be devastated.' Would he work in a hospice where assisted suicide was carried out? 'This is a tricky question. I know that assisted suicide is profoundly wrong and would not get involved in it myself. But patients who don't want assisted suicide will need doctors whom they can trust.' For Dr Whitehouse being able to work effectively and in line with his conscience is a priority. If this wasn't possible in a hospice in the UK, he might look abroad.



A change in the law to allow assisted suicide would have a negative impact on young doctors. 'They will be brutalised and suffer enormous moral distress and harm', says Dr Whitehouse. 'Doctors are taught to save lives. If the law is changed, we would be saying to them: "We also kill people to end their suffering."'

## THE ANTITHESIS OF GOOD HEALTHCARE

Dr Whitehouse is adamant that assisted suicide can never be part of mainstream healthcare. 'Assisted suicide is the complete antithesis of good healthcare', he says. 'Palliative care specialists recognise that a person is dying, meet the person there and accompany them on that journey, focussing on what is now important. The ethos is to neither hasten, nor unduly delay, death. The person is the important thing, not the suffering itself. Hastening death by assisted suicide or euthanasia sends completely the opposite message; that doctors can't deal with the patient's suffering and so death is the best option.'

There are other reasons why assisted suicide should not be part of any healthcare system. In Dr Whitehouse's view it would break the bond of trust between patient and doctor: Patients would think that if doctors think that assisted suicide is a good thing to do, they could not be trusted to give good treatment. Patients would also think that if their doctor suggests they undergo assisted suicide, it must be ok. A further problem is that resources would be diverted away from palliative care. This has happened in countries where assisted suicide and euthanasia have been legalised.

## ONE-SIDED MEDIA NARRATIVE

The media narrative around assisted dying in this country is very worrying to Dr Whitehouse. He considers it to be 'very one-sided, using emotion to cloud the truth'. Media stories about people whose relatives have died in great suffering are never complete, according to Dr Whitehouse. 'We are not given proper details of their illness, we never properly hear what care they had received, we never hear the real background to the social history or spiritual worries that might be making death unpleasant for that person. And, usually, we never hear whether they were under a hospice or other palliative care service.'

Dr Whitehouse is concerned that people do not understand palliative care. 'People think that hospices shorten people's lives using powerful medications to ease their suffering. Of course, this is not true, but it is all about perception. Powerful drugs such as morphine and benzodiazepines are used to control symptoms such as pain, breathlessness and anxiety at the end of life. However, in palliative care the doses used are just enough to control the symptoms. Research shows that used this way, lives are not shortened. In fact, people may actually live a bit longer than they would without the medications.'

## A NATURAL, GOOD DEATH

In today's atomised society people have often not seen what a natural, good death can look like. In earlier generations, extended families looked after dying people at home. It was normal to have seen grandparents, for example, peacefully passing away in their room. In addition, the shortage of palliative care provision could also be contributing to the confusion. 'It's not surprising that some people in the UK have suboptimal care at the end of life, given that an estimated 100,000 people or more, who could benefit from palliative care, do not receive it!' says Dr Whitehouse.

Dr Whitehouse sees the UK as a civilised country with a bedrock of Christian values. 'In 1939 Adolf Hitler authorised the euthanasia of a profoundly disabled child in Leipzig. This practice then expanded rapidly', he says. 'Today, reassurances that assisted suicide legislation in this country will have strong safeguards are hollow.'

Dr Whitehouse is not alone in opposing assisted suicide. Surveys show that most palliative care doctors are strongly against a change in the law to permit this practice. He says: 'We're looking at a slope which is very slippery and very steep; a black ski run really.'

Dr Whitehouse shares the story of a patient he cared for, to illustrate a peaceful death in a hospice.



***Dr Whitehouse shares the story of a patient he cared for, to illustrate a peaceful death in a hospice.***

Consuela (not her real name) was a lovely but very troubled lady whom we cared for a while ago. She had advanced breast cancer, and had undergone years of surgery, chemotherapy, radiotherapy.

She had complex social circumstances; she was from overseas, she had relationships which were problematical, she had been married several times, and had had abusive partners. A recent family suicide had led to a crisis.

Despite initial improvement on treatment, her cancer now spread, including to her bones and liver. She was already on the books of the hospice but tended to keep herself at arm's length.

Her GP asked our team to increase contact after his practice nurses flagged up that Consuela's symptoms were worsening. The nurses were visiting Consuela regularly to put dressings on infected sores on her arm, which had swollen up enormously, due to cancer recurring in the lymph channels which take fluid away from the arm. Consuela found this horrific and couldn't look at it.

One of our specialist hospice nurses visited her, and after initial reluctance, she was able to persuade Consuela to come in for a 'symptom control' admission, to help with sores, and to treat the severe bone pain caused by her cancer secondaries.

Consuela was in a very bad place, physically, emotionally and spiritually. She had had enough and felt she wanted to die. She spent nearly all day in bed. She was really suffering, in so many ways.

When Consuela arrived at the hospice, she was dismissive of our help. She asked us to 'give her something to end it all', and wanted, initially, to be alone. But after a few days of listening to her, showing we understood her, explaining her symptoms and how we could relieve them, and getting her to believe she had some living to do, we were able to relieve her pain and anguish.

Consuela was then able to sit up and talk and laugh again with staff and family. She started going round to our 'day hospice', taking part in art classes, and accepting the alternative therapy spa treatments there.

After a few weeks Consuela was able to go home for a day, and then for longer periods, eventually staying for a couple of weeks, with visits from her overseas family. She was supported by hospice nurses and our family support team of counsellors, and our chaplains.

Consuela then became suddenly much weaker, and she was brought back into the hospice. She was able to smile at the staff looking after her and share a few words before she died peacefully that night, with her physical symptoms and spiritual angst largely controlled.

# EVERY LIFE IS WORTH LIVING

It is vital that politicians read these stories  
before they vote on assisted suicide.  
Every vote against assisted suicide matters  
because every life matters.



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