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1. **Blurred lines (terminally ill/disabled) and access to treatment**

*Evidence from Not Dead Yet UK:*

“According to Advisory, Conciliation and Arbitration Service (ACAS), "***A progressive condition gets worse over time****. Examples include Alzheimer's disease, motor neurone disease, muscular dystrophy and Parkinson's.* ***Someone with a progressive condition is considered by law to have a disability*** *as soon as it starts to have an effect on their normal day-to-day activities…*”

“Section 2 (1) and Section 2 (3) of the Bill conflict with one another not only in law but also in the public perception of disability and terminal illness. The situation is further complicated by Section 2 (2) which states,

“*For the purposes of subsection (1), treatment which only relieves the symptoms of an inevitably progressive illness, disease or medical condition temporarily is not to be regarded as treatment which can reverse that illness, disease or condition*”.

“So, for example, **Baroness Campbell uses a CPAP (Continuous Positive Airway Pressure) ventilator to relieve the symptoms of her progressive disability.** **Does her use of such a device influence whether she meets the Bill’s criteria** under Section 2 (1) or Section 2 (3) or both?”

*Personal testimony 1 – Sue Elsegood lives on her own in South East London with a team of Personal Assistants providing 24-hour support. She has a progressive condition which means she cannot breathe on her own, requiring full-time use of a ventilator use and daily lung drainage. She requires full-time personal assistance and is peg-fed. She is making the most of life, contributing to her community and using her skills to benefit others.*

“**I have a type of muscular dystrophy which is a progressive, deteriorating condition with muscle wasting**. It affects my breathing muscles. I have respiratory failure and **I don’t have the strength to breathe on my own. I have to use a ventilator full-time.** The effort of breathing causes me great fatigue.

“I also **can’t cough on my own and I can’t swallow very well** so I have a tube in my stomach and I am peg-fed.

“I am a full-time powered wheelchair user.

“**I need 24-hour assistance.** For example, my ventilator tube quite often falls out so I need someone there to put it back in immediately.

“**I have very limited mobility** and need assistance to move my hands, for example from my wheelchair controls to my phone.

“**I have scoliosis and cannot sit up straight** without a special, moulded seat in my wheelchair.

“I cannot vocalise without a machine so that people can hear me.

“If I talk too much, I become very tired, and **the more tired I get, the worse my health is**.

“**I cannot go anywhere that does not have a ceiling track** hoist and a specific chair that I need in order to be able to sit over a toilet.

“If I go out anywhere, I have to take a lot of medical equipment with me including my ventilator, and my cough assistance machine which needs to be operated by my PAs to drain my lungs. This makes travel by public transport impossible and I can only travel to places if I have a PA working who can drive my adapted van.

“**It takes me 3 – 4 hours to get ready every single morning to do anything** and this, in itself, is very tiring.

“I have to travel for regular medical appointments with the following:

- Respiratory consultant

- Cardiologist

- Neurologist

- Dietician

- Continence service

- Speech and language therapist (for swallowing issues)

“On a weekly basis – if I am up to it – I have to travel to Canterbury for hydrotherapy and physiotherapy.

“I have post graduate qualifications. My vocation was to be a counsellor. After qualification I started work but I got so tired **I contracted pneumonia and experienced a respiratory arrest**. This put me into **intensive care for a couple of months**. It took more than a year to recover.

**“But things are good at the moment.**

“**It is very important to me to be part of society and to use my skills to help people**. I have two counselling clients which I do through a **voluntary programme**. We have ultimate flexibility in being able to cancel and reschedule appointments. I also engage in **co-production work with my local Council** as and when I am well enough and I **campaign on disability issues** through my local Direct Action Network [DAN] radical action campaign group.

“**I make the most of life**. I appreciate my life and the lives and the boundless potential in others. **I still have lots of things I want to achieve.**

“Last summer I took part in a **dance performance** at a local community theatre.

“I received a **life time achievement award** from my local council in 2022.

“I went on a **road trip to Spain** last September with my PA’s. It took a lot of planning but I did it!

“I do **lots of volunteer work**.

“I think disabled people should be **supported to live life to the full** and to have access to the Personal Assistance, equipment, accessible housing and health care, treatments and support we need to accomplish this right up until the end.

**“Quality of life matters and doesn’t have to stop if you have a progressive neurological condition**.

“As a post-graduate BACP registered counselling therapist, I recognise that **counselling and peer support** play a **really important role** for how people feel about life **especially when people are newly diagnosed**.

“They need to hear **positive messages** about what they can still do and how to adapt to their new circumstances. Offering assisted suicide will confirm people’s fears about how bad their lives will become when what they need are **positive interventions**.”

*Personal testimony 2 – Dermot Devlin is 45 years old and has a rare, progressive condition. Although he lives in Northern Ireland, it was the Westminster government he had to take his campaign to, to obtain access for himself and others across the UK with his same condition to a drug capable of relieving their symptoms. His whole life he has come up against value judgements about the worth of his life versus the cost of treatment and support to have a decent quality of life. Despite living with pain, fatigue, and health complications, he has achieved more than was expected of someone with his condition and has had a good life. If assisted suicide had been legal and people with his condition had been able to end their own lives with State assistance, he believes it would have encouraged him to focus on the negatives instead of fighting for what was possible.*

"My name is Dermot and I was born in 1979. I have a **rare, progressive condition** called Mucopolysaccharides Morquio Disease.

“When I was born, I could not breathe and the hospital where I was born did not have the facilities to save my life so I was rushed to another one.

“My fear looking back is, if assisted suicide had been legalised then, **how the doctors would have viewed my life** and whether they would have held back on the emergency actions to save it, or left me to pass away.

“45 years later, **I have achieved a lot in my life**. I achieved more than was expected.

“I have also experienced **many health complications** including pneumonia, stomach ulcers, respiratory issues and much more.

“Throughout my life I have battled against the idea that **my life is too expensive for society** to bear. For example, my family were told segregated education would be **more cost effective** than mainstream.

“I am currently being harassed by the Department for Work and Pensions who are telling me I have to work more hours per week otherwise **my top up benefits will be stopped**.

“**I physically cannot do any more due to severe pain and fatigue and needing an entire day every week for treatment**. Meanwhile politicians are saying that people unable to earn enough to come off benefits are **too expensive for the economy**.

**I was scared listening to much of the evidence given to the bill committee**.

There was a **strong narrative** that presented the **lives of people like me as so unbearable** that the law needs to be changed so we can end our own lives.

**Despite living in frequent pain, being in and out of hospital and needing weekly treatment that leaves me feeling tired and unwell, I have had a good 45 years**.

Had I been born into a society where the State helps people with progressive conditions to end our lives when we reach a certain stage, it **undoubtedly would have impacted on my mental health, made me doubt my potential, made me doubt myself as a person, and make me feel I was a burden on my family and friends**.

“I’ve had **vulnerable moments**, when I could have been **coerced into thinking I’m better not here**, **I’m better off dead**. Thank God that that was not in place, because I know looking back, in my dark times, **I could have said it was time for me to go**.

At those times, experiencing health complications and with my progressive condition, I would have qualified for AS under this bill.

“In the 2010s I fought **a hard campaign for many years to get treatment** called Vimizin available on the NHS for myself and others across the UK with my rare disease.

“The drug alleviates the fatigue we experience and helps our respiratory systems and increases our energy, in turn helping motivation and mental health.

“The drug was considered **too expensive** and I had to take the fight to the media and to Westminster.

“I eventually **won the fight and I receive the treatment every week** through the NHS.

“It does improve the quality of my life, but even without this treatment, my life would still be worth living, **even with the additional pain, fatigue and emotional drainage**.

“Had assisted suicide been legal at the time I was fighting for access to Vimizin, I question whether the government **would ever** have made the decision to make the drug available.

“Or whether **the attitude that my life was so full of suffering and my feeling of being a burden was so valid** that it would have been seen as **a waste of money** when assisted suicide was available instead.

“I am so thankful it was not in place ad not available to me, because **I’ve** **enjoyed my life ever since**, and I don’t want this option to be given to anybody else as the first option **making them think it's the only option**.

“I believe that everybody should have full autonomy over their own body and life, and what they do with it. However, the **safeguards are not in place** to ensure that people with conditions like mine **will always have access to all available treatment options**.

“We have seen evidence across the globe how legalisation of assisted suicide encourages **negative value judgements** placed on the lives of people who need medical and personal assistance and how many wonderful people can be caught up in it, missing out on what could be more **happy and precious moments** with loved ones before the end.

“**Without full choice there is no choice for anyone**.

*Personal testimony 3 – Chelsea Roff lives in South East London but grew up in the United States where people with anorexia can now access assisted suicide in jurisdictions where it is legal. Two decades ago, she was so severely anorexic that she was on the brink of death. Today she is the executive director of Eat Breathe Thrive, a nonprofit that helps people recover from eating disorders. Whilst she may have appeared to be making a settled choice to end her life through starvation, the malnourishment affected her ability to comprehend consequences. Luckily, she was able to access effective treatment which turned her life around. Evidence proves that anorexia, even very severe anorexia, is treatable yet many well-meaning medical professionals jeopardise the chances of recovery through pessimistic outlooks.*

“Nineteen years ago, I was hospitalized for severe anorexia. I was in dire shape**: my skin was yellow from liver failure. I was unable to stand up, walk, or bathe myself**. At 5'6" tall, I weighed 58 pounds.

“Had I been hospitalized today, physicians might have debated whether I met the criteria for a new, controversial condition—**terminal anorexia**…

“Even at the height of my illness, I was a convincing narrator of my mental capacity. I was remarkably lucid, **yet could not comprehend the risk that starvation posed to my life**.

“One of the most striking **neurological effects of starvation** is how it distorts your emotional perception of risk and reward.

“I felt comfort when I was hungry, but apathetic about my failing organs…

“Many doctors had little hope for my recovery. My care team tried everything—psychological therapies, psychiatric drugs, and residential treatment. I was called obstinate, stubborn, intractable, and treatment-resistant. **I felt hopeless and despondent, a burden to my family**.

“**If the option for assisted dying had been available, I would have taken it.**

“After 16 months of state-mandated treatment, I did recover. Today, I run a nonprofit that helps people with eating disorders. I have not weighed myself or counted calories in almost twenty years.

“**For years, I believed I had a chronic and likely terminal disease.** I was told by well-meaning medical professionals that relapse was inevitable. I met people who had cycled in and out of treatment for decades—they said anorexia never goes away…

“These ideas are **unscientific and misleading**, eroding the sense of agency and self-efficacy you need to recover… Anorexia is difficult to recover from, but it is a **treatable condition**…

“Anorexia has the highest mortality rate of any psychiatric disorder—but with effective treatment, up to 72 percent of patients make at least a partial recovery and nearly half recover completely.

“Assisted dying laws require physicians to deem with "reasonable medical certainty" that the patient will die within six months.

“But in mental health, there are no standardized tests to determine disease progression... Physicians' assessments of who is terminal are **almost entirely subjective**, carrying life-or-death consequences.

“A diagnostic term is powerful, and especially for those with psychiatric disorders, a terminal one can **become a self-fulfilling prophecy**. Calling treatment "futile" and death "inevitable" can itself **diminish a person's capacity to make sound judgments about whether to continue living**.

“The creation of "terminal anorexia" will **inevitably sow feelings of cynicism and hopelessness in people with a real shot at recovery**.

“Further, a diagnosis of terminal anorexia may **gloss over widespread failures in healthcare**. Many patients desperately want to recover but **never receive adequate treatment**…

“This makes **the slide toward palliative care** all the more chilling…

“**We can respect a person's autonomy without colluding with their most despairing thoughts—the feeling their life is not valuable.**

**“I am alive today thanks to those who never gave up on me, and for that, I will always be grateful**.”

Extracted from: <https://www.newsweek.com/i-was-anorexic-would-have-chosen-assisted-dying-1870648> with permission from Chelsea.

1. **Coercion and quality of life judgements**

See also: Personal testimonies 1, 2, 3, 9 and 10

*Personal testimony 4 – Lucy\* is in her thirties and lives in North West England. She has cerebral palsy and uses a wheelchair. Twice medical professionals have tried to coerce her into agreeing to a DNR. She has also experienced discriminatory treatment that denied her access to ICU. These experiences reflect the attitudes her parents experienced when she was born where the quality of the life she would have was questioned. They have made her feel that medical professionals view her as better off dead.*

*\*not her real name*

“Prior to Covid I was admitted to hospital with a UTI. I was really unwell. My carers had to battle for them to take me seriously and take me in. Then I was discharged early and ended up having to go back in again.

“In that period, I had this woman, this staff nurse and a consultant come into my bed, **trying to persuade me to sign a DNR**. I said no, I am not signing. They said, well, if you had resuscitation, very few people have had the lack of oxygen you had prior to birth – which gave you cerebral palsy - and you could come out a lot worse, a lot more disabled.

“I said no and I thought two people that I’ve never seen before in my life tried to persuade me to sign a DNR.

“They said we’ll have a meeting about it, your consultant, your care manager, your parents and you yourself. It was **like they were bullying me into signing a DNR**. They **tried to coerce me** but I wouldn’t budge and my parents backed me up.

“Now if I was able-bodied they wouldn’t do this would they?

“A similar thing happened later on in 2021.

“I was in hospital and I fell asleep, I was breathing but they couldn’t wake me up and they panicked and they rang ICU and **they wouldn’t accept me**, they said being on a ventilator would be too traumatic for me.

“I argued and said I wanted to try a ventilator.

“Now, it wasn’t comfortable. I couldn’t speak and they sedate you to get it in but I wouldn’t say it was traumatic.

“It was how **they didn’t ask me**. And I’m compus mentus. I haven’t got a learning disability, no one has power of attorney over me.

“They also **didn’t like it** that again I wouldn’t sign a DNR. Because ICU wouldn’t have me, they said you’d have to be resuscitated on a ward. I said fine.

“Before I went home, they tried to find carers who could do the CPAC machine. They were going to put me in a nursing home. I said I will die if I go in a nursing home. Luckily, they found a company with trained carers.

“I feel my health care and **my survival depends upon people who think I would be better off dead**.

**“Now I see the NHS as a totally different place.** All the hospital programmes showing doctors and nurses as there for the people. After my experiences it feels like a joke. They look at you and make judgements. How old is she? Will see have a quality of life?

“My view of the NHS is **totally clouded**.

“It’s like going back to olden times.

“When I was born my doctors told my Mum **I would never have any quality of life** and **I’ve done so many things in my life**, things that able-bodied people haven’t done.

“How dare they judge and bully your parents, **she won’t be able to achieve this or that**.

“It’s all about money in the end isn’t it?

“I don’t know if it’s about **quality of life**, that **they think they’re doing it for you**, or if it’s about the **NHS budget and they’re doing it for the purse**.

“I want to be anonymous for this. Fear of comeback. I live in the town where it happened.

**“My life is hard as it is**. Twice I have been mugged, my bag taken off my wheelchair while I am sat there just going down the road.

“Also, you have to fundraise to get anything now. Fundraise for my electric chair – don’t social services give you those, don’t you just get everything? – NO – it isn’t handed to us. We have to wait and we get turned down for things.

**“If I wasn’t such a strong fighter, I’d be dead**.

“If my **parents were overcome by medical professionals** – if the doctors say we should then we should – then I wouldn’t be here.

“Doctors can be **very intimidating**.

“In the hospital, **I said I’m not dead yet**, I kept saying.

*Personal testimony 5 – John Smith is 59 years old and lives in Northamptonshire. He has been in and out of hospital his entire life. He understands the importance of good doctor-patient relationships and of the trust that will be broken if the nature of that relationship changes by giving doctors a role within assisted suicide. While he was in intensive care last year a DNR notice was imposed on him by medical professionals who questioned his quality of life, which his partner, family and friends had to battle to have withdrawn. He has personal insights into how the everyday oppression experienced by disabled people exerts a pressure that could easily lead to patients believing they should opt for assisted suicide although it is not their choice. He also supported a Deaf friend dying of cancer who spent his last years fighting for the communication and support services to which he was entitled and who talked about assisted suicide in his bleak moments when his needs were not being met.*

“I have had numerous dealings with doctors and medical professionals over the years. I have been in and out of hospital and had **50 + operations over the course of my life**.

What I have learned is **the importance of maintaining a partnership between a doctor I trust and myself** to ensure I have a good life.

If that **same doctor assisting me to live can now put me forward to have my life ended** then that breaks any kind of doctor – patient relationship and that relationship is fundamental, in my view, paramount, as is trust and giving them the power to approve me for assisted suicide would **break that completely**.

What has impacted me recently was an experience just last year when I was in hospital involving a DNR.

I had a bone infection and it led to sepsis. I was unconscious and admitted to ICU. I had kidney failure.

My partner was told to prepare for the worst.

He had never seen me ill, he had only seen me as an **active disabled person**.

And it’s **the times when we are ill that we lose control over our lives** and come to be at risk from subjective judgements.

I had no relationships with the doctors at that hospital I was in.

My partner came to see me and was told by doctors there was **a DNR put on me as I had no quality of life and it would be best if I was left to die**.

My partner contacted my friends and my brother who is a nurse and they had to **advocate for this DNR to be taken off me**.

During my experience of sepsis, I could **easily see how feelings of guilt could lead to me agreeing to assisted suicide**, not because I wanted it but because of guilt about the impact of my illness on family and friends, feeling it was **my fault they had all this extra stress** on them.

My partner doesn’t get the mental health support he needs. He had to deal with me being ill at the same time as fighting against my DNR notice.

The **internalised blame is so deep-seated** – especially for disabled people who have been told our **whole lives that our lives not worth living**.

When a feeling like that is so deep-seated how can a doctor possibly spot it?

No safeguards will be able to tackle **issues like this that are created at a societal level**.

And then there are the conditions we live under – so not just **continuously having to challenge assumptions** about our quality of life, but also having to **fight for the support we need** to have the decent life we want and are capable of.

A friend of mine who I previously worked with when I was a youth worker was diagnosed with cancer and less than 6 months to live six years ago.

He died last year.

For those **last years of his life, he had to fight continuously**.

His oncologist didn’t know British Sign Language and **kept forgetting to book interpreters**.

At his palliative care appointments, they **relied on his partner to interpret**, which put an extra weight on the partner.

It also meant he **never had the option of privacy**.

Social services tried to **remove his night-time support package**. So, he had to had to take a **judicial review against his council**. He won. In fact, he won three legal challenges against them.

He set up a **peer support group for Deaf people with cancer** because there wasn’t one available and so they could share experiences and campaign together for things like BSL interpreters at health appointments.

All these things he did were amazing.

But I find it **heartbreaking that the systems were not in place** for him.

He shouldn’t have been **fighting like this at the end of his life** when he was dying.

At times **he did talk to me about assisted suicide** when times were hard and **his needs weren’t being met** but then a few days later he would get better support and **would change his mind**.

People **who are dying shouldn’t have to fight** for suitable housing, fight for social care support, fight for our communication access needs to be met at our own medical appointments and we shouldn’t have to fight against **assumptions that our lives are worthless**.

**This is why we need to fix the foundations.**

**Rather than stick an assisted suicide service on top of failing, broken systems**.

As someone once said: “It seems to me that all suicides in circumstances of need have the undoubted character of murder. The question of a right to suicide will only make sense where no material motives for suicide exist and where we are all guaranteed a means of existence.”

*Personal Testimony 7 – Maureen Stagg lives in Croydon. She is 74 years old and a retired office manager. She was diagnosed with bronchiectasis at the age of three and has outlived the life span she was told to expect. Her mother acquired Parkinson’s and Lewy Body Dementia. She was moved into a care home after her partner could no longer care for her. There she developed pneumonia and was admitted to hospital on an emergency basis. A consultant advised Maureen to agree to her mother being put on the Liverpool Care Pathway. She agreed but soon realised it was the wrong decision. Luckily, her mother survived and died a few years later in much better circumstances.*

“I have a chronic, long-term health condition called bronchiectasis. It means I am frequently ill and have a permanent cough. It has affected my confidence. I lost time at primary school due to chest infections and found it difficult to make friends. Society is a lot more hostile now even before Covid. I love the theatre but am nervous about people who turn and mutter when I cough. On the bus once I was spat on because I was coughing.

“My whole life I have relied on medical professionals who treat me and keep me well. I trust them and **for most of my life have been too uncomfortable and lacking in confidence to question them**. My daughter now comes with me to appointments.

“Back in December 2009, my mother, who was in her early 80’s, was admitted to hospital with pneumonia. She had Parkinson’s with dementia and had recently moved into a care home after her partner could no longer care for her at home because he was about to have knee surgery. She was clearly unhappy in the care home.

“I was able to be with her in the local hospital very soon after she was admitted and my adult children started their journeys to join us.

“On the first afternoon she was admitted she was put in a bed on the urgent care ward. She wasn’t conscious.

“The following morning a doctor asked to speak to me and I asked my eldest daughter to be with us. She is disabled too and at that time wasn’t very confident either. And to be honest **neither of us were in an emotional state to be able to process the question at that time**. We weren’t even sitting down, just pulled aside on the ward.

“The doctor explained to us that **my mother did not have a quality of life** – with a progressive physical condition and dementia – and now she had pneumonia. She was **not a candidate for intensive care** and **therefore she would be put on the Liverpool Care Pathway**.

“This meant the withdrawal of all treatment other than fluids and painkillers such as paracetamol.

**“We were not given any choice in the matter but it seemed the right thing under the circumstances**.

“We all stayed with my mother and eventually she was moved to a side room.

**“It became clear over the next few days that she wanted to live**. Despite her dementia and her inability to verbally communicate, we knew her. We realised that **it had not been the right decision – just the one the consultant chose.**

“Close family spent five days and nights by her bedside and other family visited.

“My step-sisters brought their father, now in a wheelchair due to recent surgery, to visit. **It was obviously a very special moment for them both.**

“After five days it became clear that my mother had no intention of going anywhere, and the hospital restarted treatment and fed her.

“Once she was well enough to leave the hospital, I found her a nursing home to move to instead of going back to the dismal care home.

“She was **much happier there and much more herself**. No matter how far the dementia progressed, she still had a twinkle in her eye when the male nurses were in attendance!

“Two and a half years later her partner succumbed to cancer. I went to visit her and told her he was gone. Despite the dementia having progressed to the point she had to be reminded how to eat, I knew she understood as she became very upset.

“A couple of months later my mother died.

“It was clear that her will to live was linked to her love for Gordon. Once he was gone, she felt it was her time too.

**“She died in her own room with her family around her,** holding my niece’s hand.

“**Had she died under the LCP** a few years earlier **it would have been much harder for us to cope with**. We would always have blamed ourselves for not fighting for her. Our last memories of her would have been of watching her fight to breathe **knowing someone else in the same situation whose life was considered more valuable would have been treated**.

“The reason why I feel this is relevant to the assisted suicide bill now passing through Parliament is because it demonstrates **how ordinary people can feel pressured into not challenging a decision about life and death on the basis of what they think the medical professional believes is the right thing to do**: someone they think is **more important and whose opinion is more valid than their own** but who may well be putting resource considerations or subjective judgements ahead of what is best for the individual patient.

“To not challenge an opinion that you don’t fundamentally agree with can lead to intense emotional pain, regret and self-blame.

“It is also important that **family members are able to input into assessments** and to **appeal decisions** to approve patients for AS.

“I am aware of cases in jurisdictions where AS is legal where family members have not had the chance to speak to their loved ones about their decision and who are **haunted by regret, anger and upset and self-blame for the rest of their lives**.

“Whereas the patient may be experiencing depression, it could be that **changes are possible** which will allow them to **live longer and experience more special moments and to die in a happier place.**

**“I don’t understand why Parliament is not hearing the full range of experiences and voices relevant to this really sensitive and difficult subject.**

*Personal testimony 7 – Stacey\* is in her late forties. She lives in London and has accessed mental health support since she was 16 years old. She has personal experience of coercive control and understands how difficult it is to assess whether someone with experiences of abuse is making a choice for themselves or what they think other people want/expect from them.*

*\*not her real name*

“I am a disabled woman with a history of abuse whose mental health characteristics attract relationships that fit the definition of **coercive control**.

“I am not alone in this as disabled people are **three times more likely to experience domestic abuse** than non-disabled people and disabled women **twice as likely to experience sexual violence**.

“I am also aware of statistics that show women are **disproportionately represented** in deaths by assisted suicide.

“Internalised oppression and **the idea I am not good enough** compared to non-disabled people affects my confidence and self-esteem. **My default position** is that I really am **worthless**.

“The **purpose in my life is helping other people** and trying to make sure no one ever feels the way I have at times.

“However, my desire to help others and bring out the best in them easily **becomes detached from any sense of self protection** and so I am easily taken advantage of.

“Even when rationally, I have known, for example, that my partner was deliberately pushing my buttons to get something from me, **on an emotional level I have believed** what they are saying and given in to avoid the unbearable feelings of being a bad person, even though it meant hurting myself for example giving them money I couldn’t afford or doing something for them when I didn’t have time and it burned me out even more.

“This split between emotional and rational beliefs causes **cognitive dissonance**. Too much cognitive dissonance is **literally mad-making**.

“This then feeds into the **gas-lighting** which a mental health diagnosis and my open-ness about it also enables.

“Throughout my life I have had experiences where professionals – in health, psychiatry and counselling – have seen my formal diagnosis and **assumed that the problems in my life were all down to my mental health and associated behaviour** and not picked up on the abuse I was experiencing.

“At least until a certain point where something bad happens that makes it click for them or the mask eventually slips but this may take a while.

“These kind of experiences make you **question your own identity**. If it goes on long enough, instead, **your partner becomes your identity**. Meanwhile there is a sense of **hopelessness and despair**. How can you leave when it means losing yourself and what has become your own identity?

“This is all the more so because in these types of relationships you can **become very isolated away from family and friends**.

“When you start to believe what another person tells you, how then is anyone going to pick up that you have become **detached from your own needs and interests**?

“Only possibly through a relationship with a professional who has come to know and understand you and your situation **over a period of time** and with whom you have **built up trust**.

“Maybe also **input from other people in your life** – not to remove your own autonomy but who can provide information that is needed to make a full and fair assessment.

“The other thing I experience especially with strangers is both **a deep-seated need to please** - regardless of what my own needs, interests, views and wants are and **regardless of the consequences to myself** – and such a strong ability to empathise and to see things from another person’s point of view that **I lose my own perspective** and what is best for me. In this way I can be easy to influence.

“For this reason, I now find life safer and more stable if I keep myself as isolated as possible – rarely leaving the house or answering the phone.

“I am not an anomaly or rarity. My primary diagnosis is shared by 2 – 3%v of the UK population but most aren’t in a position to get their voices heard or have their experiences understood.

”I think it is really important that issues around **coercive control and the long-term impacts of trauma** and abuse are given the **proper time and consideration** with respect to passage of this bill and how to ensure someone is making a choice that is truly what they want.

1. **Relieved at not having had access to AS**

*Personal testimony 8 – Kevin Caulfield lives in Shepherd’s Bush. He is severely physically disabled as the result of a neurological condition which nearly killed him 27 years ago. At the time he had a prognosis of less than six months to live. Since then, he has adapted to his new life and is relieved he did not have access to assisted suicide.*

**“27 years ago**, I was diagnosed with a ‘terminal’ HIV-related neurological condition **with a prognosis of less than 6 months**. I was terminally ill and a Disabled person in law.

“I was in a terrible situation, **the depths of which were crucifying**, both physically and mentally with **a rapid onset of multiple impairment**.

“But, as you know, I am still here.

“At that time, I was **desperate beyond words**, and I may well have **jumped at the opportunity** of ‘assisted dying’.

“I could have argued easily that I **met all the criteria proposed with this bill** and who would have fought for me to stay alive? After all I am articulate, my life was going to be limited, and it would have been **my ‘choice’**.

“But it would have been a very **loaded choice**.

“In my view **not a real ‘choice’ at all** because:

• I was scared to death with **no access to tailored intensive mental health support** (I had great clinical care but that is really not enough. Clinical staff didn’t or couldn’t talk to me about my situation because they had no time.

• I felt I had absolutely no control and **my overriding state was one of panic** as I was deteriorating so quickly. Focussing on ‘assisted dying’ would have given me a focus, when **what I really needed was additional support**, to spend more time with loved ones, deal better with my affairs and to have very frank, more time-consuming **conversations** on how to deal with multiple symptoms **with healthcare professionals** that just wasn’t available to me.

• HIV / AIDS was treated as a plague/ and people with the condition were **treated often as less than human** – psychologically pushing you towards suicide or making the option of assisted dying seem more attractive.

• **I lost my home because it was by then inaccessible** to me as I needed a wheelchair to get around and an adapted bathroom with a hoist.

• I had **no access to ‘peer Support’** from anyone going through something similar, no support from anyone other than professionals and friends / family who could not help because it was not within their experience.

**Almost everyone around me wouldn’t have believed then that I could or would want to survive**. Nearly everyone would have felt that assisted dying was a good option and putting all of the above together who could blame them?

I am telling you my personal experience because it is highly relevant, but not because my personal experience on its own is enough to be against the Bill. It isn’t but it’s also about the current state of the NHS and ‘end of life care’

• I am concerned that **the NHS and public services are currently neither equipped or resourced appropriately to respond to the needs of ‘terminally’ ill people**.

• The NHS is still in crisis. A friend of mine just spent over two weeks, nearly three, in an A&E bed the whole time at St Marys, waiting for an operation. A fellow Shepherds Bush resident. So where are the trained staff and support services to deliver the bill going to come from right now? The time and effort to set up and embed a new service will lead to **‘terminally’ ill people being failed**.

• The current benefit system adds to making it hardly worth living with **some terminally ill people reduced to near destitution** because of the decimation of what support is available. Yes, terminally ill people can be fast-tracked, now if they have 12 months or less to live, but the rates they are paid at is **barely enough to live on** and the application process is harrowing. Then there is the stigma of being on benefits due to the demonisation of benefit claimants by politicians and the media. 27 years ago I could manage, but if I was in the same situation now it would be another tick in favour of turning the lights off sooner rather than later.

• Having experienced the **removal of fluids and food** often portrayed by many as an act of mercy, it was the **most barbaric, painful, merciless act** I have ever experienced. The methods for bringing about assisted dying need to be thoroughly looked at.

• Hospices and related groups need to not be reliant on charity donations in part to meet needs.

• **Mental health support** to be properly resourced.

• **Social care support** to be properly resourced and free at the point of need to all.

• Our human rights to be able to access **the support we need to live in dignity**, to be protected however long we live.

You and I both know we are **a very long way from any of the above being delivered**. This is **not about wanting perfect services**, it’s about wanting services that meet **the basic, fundamental needs of disabled and terminally ill people**.

Instead of rushing to pass this bill, I urge MPs to advocate for **improving community care, particularly palliative care and support services**.

**Many people still struggle to access adequate end-of-life care**. We should ensure everyone has access to **high-quality care and pain relief and where possible access to peer support**.

“It is the combination of all of the concerns together that lead me to my opposition to legalisation of assisted suicide.

“I may well once again end up in a similar situation to the one I was in 27 years ago and I would still oppose this legislation. I have no religious faith and for me it is not about living for living’s sake. Please carefully consider the potential unintended consequences of a rush to legalisation.”

*Personal testimony 9 – Nik is 53 years old and lives in Surry. He has motor neurone disease and has been terminally ill for the past five years. He uses a motorised wheelchair and breathing apparatus. He is gradually losing the ability to move any part of his body and knows he could die tomorrow by choking on food or on his own saliva. He says he probably would have chosen assisted suicide had it been available when he was diagnosed. He is now opposed to assisted suicide and says life is precious. He is grateful to have seen his children grow up. His eldest daughter is engaged to be married. He says better conversations would help people who are terminally ill make the most of the time they have left with their loved ones, and so choose not to end their lives early.*

"I prided myself on my health and fitness. Twenty years ago, if you were to say to me that I'd be in a wheelchair, I'd be like '**Nah mate, it's all right. I'd rather go**.'

“I have had healthcare professionals telling people that are visiting me to say goodbye as I am on my last legs.

“[Had AS been available when I was first diagnosed] I would have talked to my kids about it and they would have supported me.

“[The legalisation of assisted suicide would create a] **very subtle but very insistent background noise**.

“[People who may feel like a burden to their loved-ones might choose to] end their lives because they **feel like they ought to for their children's sake**.

"It's the good people, the people who are trying to be virtuous, who are dignified and trying to do the right thing - **they are the ones I'm worried about** and think [this law] could be problematic for.

"It will be the grandmother in the care home that doesn't want to spend all the money she's got in her savings account because she wants her grandchildren to get it. It will be people like her who seek to end their lives."

"This is despite the fact her grandchildren **will be likely to value the last of the time they have got** with her more than they are an additional £10,000 or £20,000.

"People will make a [life or death] **decision based on internal judgements that aren't necessarily accurate** because **people don't have honest conversations about death**.

"Ironically, I think what people say and do at the end of their lives is utterly defining of their life.

“The point was made several times [during the second reading debate] that since the last vote nine years ago there has been very little improvement in palliative care.

“[Legalisation of assisted suicide] **redefines the norms of our society** in a way that is, I think, **terribly dangerous.**

“However you look at it, it’s just **literally not the right time for us to change the law** on this very problematic issue.”

Extracted from: <https://www.bbc.co.uk/news/articles/c3vln4pn3gzo> and <https://www.bbc.co.uk/news/articles/cvg720lrjrmo> and <https://www.youtube.com/watch?v=vYUTgpe9jd8>

*Personal testimony 10 - Fiona Robertson is a disabled writer living in Aberdeen. She has a fluctuating condition which has left her unable to leave her house for years at a time. After having to leave her Theoretical Physics course when she became disabled, she would have opted for assisted suicide had it been an option. She was given a lifeline by other disabled people who showed her there were still things she could do. She is concerned that disabled people who meet the bill’s criteria will opt for assisted suicide as a result of society-wide oppression and discrimination.*

“I have no moral objection to assisted suicide in principle.

“But I have spent 25 years as a disabled person in this country and am **intimately familiar with the medical and social systems** it will come into.

“Disabled people have **warned again and again** when we can see a situation arising that will cost us our lives and **again and again our concerns are dismissed**.

“Welfare reform is one example. I myself attempted suicide after a DWP tribunal. There have been thousands of lives lost but instead of making changes to prevent more benefit deaths, instead the government has doubled down.

“When the pandemic started, we warned that our lives would be deprioritised by doctors who think it is a **kindness to let us die** and we were told what we were suggesting was defamatory and hysterical. Then **the unlawful use of DNRs emerged** and there was an out-cry.

“Assisted suicide is another such example.

“I don’t see how it can work **if the very system that is meant to impose the safeguards** to protect us is the **same one that devalues our lives** on a daily basis.

“I have a fluctuating condition.

“I have spent years at a time house-bound, mostly bed-bound.

“I can tell you without a single shadow of a doubt had this been an option in the early **years I would have taken it**.

“I told friends that if anyone found me after a suicide attempt, they should **not call for help** and they agreed – because of course it makes sense that **being disabled my life was not worth living**.

“I cannot tell you how many people over the years have told me **they would have killed themselves if they have been me**.

“It was years before I met other disabled people **who showed me another way to live**.

“During Covid I wrote a book to explain to newly disabled people that their **only options are not just recovery or suicide**.

“Chronically ill people experience medical care differently to other people – we have to **fight to be taken seriously** by the very services we rely on for survival. **It’s exhausting**.

“Everywhere we look disabled people get told suicide is not just an option, but is the **best solution** for us and our families.

“Coercion is exerted on us to end our lives through **society-wide oppression and discrimination**.

“Without adequate support to meet our needs, family members have to leave work to support us and/or burn themselves out.

“If I became so unwell again my husband had to look after me, leaving his critical job in a hospital, **how could I not see myself as a burden?**

“Half of people say they would **rather be dead than disabled** and that view is more prevalent the higher the income bracket. Healthy people think needing help is the end of the world.

“In a society where **asking for help is seen as shameful** but **asking for suicide is seen as dignified**, legalising assisted suicide will kill people who don’t want to die that soon.

“And there are just not enough of us who understand what is important in life to guide those who are newly diagnosed and want to be shown another way.

“My condition is now at the point where most of the freedoms I had been able to regain have been lost again, and as **my partner has to take on more responsibilities for care**, as I am able to do less and less, **it is hard not to hear that voice again**.

“The one I hear from government ministers and people in the papers and everywhere else, **saying I'm a burden**.

“The one that says **my life is too small to be worth all this hassle**.

“And instead of offering ways to make life more bearable, instead of trying to convince us suicide isn't the answer, **you just offer to do it for us**.

“Not in the first stage, sure.

“But that's where it ends up.”

1. **The importance of access to good support**

See also: Personal testimonies 1, 2, 5, 8 and 10

*Personal testimony 11 – Nicki Myers lives in Cambridge and has pulmonary fibrosis, which is a terminal condition. In 2017 she was given a prognosis of five years. She now lives knowing she could die at any time. She is 99% bed-bound and lives each day to the full. She has the benefit of support from her local hospice, peer support from other people in her same situation, funding for support that enables her to stay at home and disability benefits that just about keep her head above water financially. She has an advance directive that sets out how she wants to die. It gives her comfort and means she is assured she will not die in pain. She knows not everyone has access to the full range of support she does. During Covid her GP contacted her and pressured her to agree to a DNR on her medical notes. This damaged their relationship and Nicki questions how far she can now trust the GP to support her to keep living. She thinks society has a lot to learn from people who are terminally ill.*

“I have been a disabled person my entire life and at the age of 44, I was given a **terminal diagnosis of pulmonary fibrosis** which has put me in ICU 4 times.

“Because of my pre-existing disability, I was not given the option of a **life-saving lung transplant** so my situation now is that I am **99% bed-bound**.

“I have made **a good enough life for myself in this situation**.

“**Every day I’m here is important.** I have no desire to be ‘put out of my misery’.

“During lockdown, **I learned to draw and paint** through online courses and now I'm on the advisory board of a national adult education charity.

“Until recently I taught music classes online.

“I am still able to **take part in the lives of my children and 6 grandchildren**.

“I have Continuing Healthcare funding for my care at home. And yes, it is reassessed every year and for some random reason even though I will never get better, it could be taken away and assessments are exhausting and stressful but the care **keeps me out of hospital**.

“I also have the **support of my local hospice**, Arthur Rank, and, **without that, I would not cope**. They have helped me with medical and practical issues. They have helped me create a **very detailed advanced directive** about what I want and don't want in terms of treatment and interventions now and as my condition progresses.

“We also have weekly social zoom calls and that **social interaction with other people in similar positions is absolutely crucial to my well-being**.

“The document the hospice doctor wrote with me sets out that **in my final days, medical care can be provided at my home** and will include **intravenous sedation and pain killers** that may negatively affect my breathing and that may **slightly speed up my death**.

“This is totally legal and available to people under the hospice but not everyone has access to such a service, yet they should and it should be 100% funded by central government.

“I have okay days and awful days but compared to some people with this diagnosis, I'm pretty lucky because of all the support I have that I know others in similar situations aren’t able to access. When I read the proposed Bill, my first thoughts went to them.

“One privilege I have compared to other sick, dying and disabled people is that the Department for Work and Pensions have left me alone for a few years and I'm on an **appropriate level of social security**.

“That's all going to change very soon as we're moved to Universal Credit, but for now, I'm just about okay and I try not to think about the debt I have with my energy supplier.

“**Many people in positions like mine are destitute**.

“My first language is English and I'm pretty good at negotiating the various systems that we have to ensure my needs are met. **Others are not so fortunate**.

“I am at a point where I can just about cope with it all.

“If anything goes wrong with my care, medication, level of isolation, ability to do the activities I enjoy, financial stability, **my mental health suffers** and **maybe if I was asked about assisted dying at those times, maybe I'd say yes** because the fundamental things I need aren't in place.

“**So many people have never had those fundamental needs met** and I strongly believe that the UK should not be asking these questions about assisted dying until every system we rely on and service we need has been provided.

“What I also worry about with this Bill is **it will change my relationship with my doctors and the medical profession**.

“It’s already been damaged during Covid.

“I was one of the people who was **called by a GP that I'd known for years** who asked me very abruptly, **whether I would agree to a DNR** in the early months of the pandemic - It wasn't really a question, more an expectation.

“I just pointed them to my advanced planning document which already sets out what I do and don’t want when I am close to death.

“But **that conversation was damaging to the relationship** and how far I trust this GP on whom I rely for ongoing medical treatment.

“I feel will get even worse if this Bill passes into law. I would be **constantly questioning whether these people really wanted to treat me or not**. Disabled, sick and dying people already know that healthcare is being rationed, so we have to be strong advocates for ourselves and each other, already.

“I watched the debate for the second reading closely and **so many of the arguments in favour of this Bill were riddled with disablism**. People think they couldn't go on living if this or that happens and, God forbid, they need assistance with personal care.

“**Those views devalue the lives of everyone who requires assistance** to do everyday tasks, including palliative care patients.

“It's almost that if people think they never need help with anything.

“People can and do **adapt all the time** to acquired disabilities, long term health conditions and terminal diagnoses.

“**The** **human spirit is amazing**.

“My online hospice zooms are filled with tales of **expert problem solving**, so much **love and support** and a fair of amount **raucous laughter**.

“If there is the **political will to fix fundamental services that palliative care patients rely on**, then maybe, one day, it'll be ethical and safe to have a national conversation about assisted dying, but **that time is not now**.

“Society has so much it could **learn from people who are terminally ill**, like **how to make the most of each day and how to live in the present**.

“People live differently when they receive a terminal diagnosis. Every hour of the day that it’s possible to be active is **spent wisely** and has **so much more meaning**.

“It would **benefit society** far more to be looking at what it **can learn from disabled people and people with terminal conditions** instead of seeing us as objects of pity to put out of our suffering.

“From those in favour of the bill I have kept hearing that waiting for palliative care and other services to be perfect means putting off what they regard as an "urgently needed" change in the law to allow assisted dying and we "mustn't let perfect be the enemy of good".

“I disagree.

“**This is a cop out,** **giving up on ever having adequate services**.

“Services have never been perfect and we accept that but **dying people are being let down by sporadic or non-existent palliative care now** and **this is completely fixable.**

“**We know what works**.”