

Dear Peers @UKHouseOfLords

I do feel truly sorry for people who are suffering. We should care for them properly with specialist pain relief.

But many people with Down syndrome and their families are really scared and upset about the Assisted Dying Bill.

I am asking for your protection. Please keep us safe.

We are worried about being pressured into choosing to die if the people we know and trust aren't there.

- We might not understand what is really happening
- We might be pressured into asking to die
- We don't want that to happen to us
- Other people try to speak for us, but do they really know how we feel?
- I am worried that deep down, they might not care about us.

We need people we know and trust, who love us and know how we communicate, in order to help us understand. We need people who really listen to us, not just an 'advocate'.

- I find it hard to say no. I usually say 'possibly' instead. My body language will tell you if I want to say no.

We were told we would have a voice – but we were not allowed to speak.

We were told there would be rules to keep people safe - but those safeguards were taken away.

Some committee members and supporters made comments that hurt and worried us:

- Kim Leadbeater called our concerns “noise”
- Kit Malthouse asked how to stop people from saying that “vulnerable people are being ignored”
- Dame Prue Leith said “causing family anxiety” could be a “valid reason” to die
- Dr Henry Marsh even said, “if a few grannies get bullied into [suicide], isn't that the price worth paying?”

This is not acceptable. It is insulting and one-sided. It shows that they are ignorant about our lives. It shows they don't care about us.

We are not collateral damage.

Our lives are worth living.

We have families and friends, we laugh and cry, we fall in love, some of us get married and have jobs. We try our best. We have worth. We have every right to good healthcare, pain relief and if necessary, hospice care, just like anyone else.

BUT

We already know many healthcare staff don't think our lives are worth living and society sees us as a burden. We are targeted for screening.

How would you feel if people didn't want you in the world?

This has scarred me for life.

NOW

We are worried about being pressured into dying by people that do not see us as equal human beings.

When the House of Commons voted for the Bill, no one listened to us.

- Now we need you to hear our concerns and be our voice.
 - Please make sure there are proper safeguards.
 - Please protect us.
 - Please keep us safe. **It is better to be safe than sorry.**

Include us. Invite us to speak. Hear our voice. Please work with us.

Follow the National Down Syndrome Policy Group's

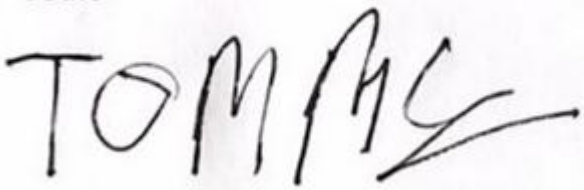
#NotCollateralDamage #SafeNotSorry campaign

because **our lives matter** and are worth living.

I am not collateral damage.

I am an advocate, actor, author, public speaker. I am a friend, brother and son.

I am Tommy Jessop.

Yours


Tommy Jessop
Ambassador, National Down Syndrome Policy Group