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## **Tommy Sheppard MP**

In our society, where equality and compassion are revered virtues, it is deeply troubling that only the privileged and physically able among us have the means to exercise their right to die with dignity. The stark reality that some of our fellow citizens are compelled to travel to Switzerland, far from their homes and loved ones, in search of a peaceful end to their suffering, while others are denied this option due to financial or physical limitations, is a testament to the systemic inequality that persists within our legal framework.

We must confront these inequalities and strive for the most compassionate and inclusive laws possible across the United Kingdom. Every individual who is enduring unbearable suffering due to a physical, incurable condition deserves the right to make informed choices about their own end-of-life care. It is a matter of basic human dignity that we afford them this autonomy and respect.



Parliament must address this pressing issue. The current law is unfit to meet the needs and desires of those facing terminal illness and intolerable pain. We cannot, in good conscience, continue to export compassion to Switzerland while neglecting the suffering of our own citizens at home.

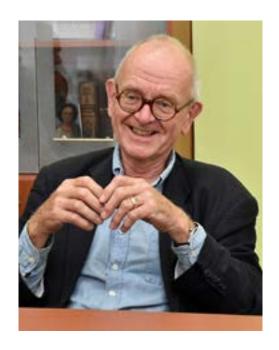
In this report, we confront the uncomfortable truths surrounding assisted dying in the UK, and we advocate for change. It is my hope that this document will serve as a catalyst for meaningful dialogue and action by those with the power to enact change. Together, let us work towards a future where every individual has the right to die with dignity, surrounded by love and supported by a compassionate and safe legal framework.

Tommy Sheppard, Member of Parliament for Edinburgh East.

Scottish National Party (SNP)

## **Dr Henry Marsh**

The practice of medicine is not just about saving lives and healing the sick but also about the relief of suffering. All doctors know that despite good palliative care, dying can sometimes involve great suffering, both for the patient and the patient's family. Furthermore, there are incurable degenerative diseases - such as motor neurone disease - which can follow a protracted course with much suffering before the patient's eventual death. All doctors also know that good medical practice is based on evidence, and that "expert opinion" is the lowest form of evidence. Assisted dying - and it can take many forms - is now legal in many jurisdictions, so its benefits and potential problems can now be discussed in terms of evidence, rather than in hypotheses from self-proclaimed experts about what might happen.



Switzerland has had more experience for longer than any other country with assisted dying and many UK citizens have gone there for an assisted death. The law in Switzerland makes a clear distinction between assisting suicide and encouraging suicide – a crucial distinction that the relevant law in the UK singularly fails to make. There are clear safeguards and careful regulation of assisted dying in Switzerland. There is simply no evidence that abuse and coercion occurs – the most common hypothetical objection raised against assisted dying by its opponents in the UK.

It is important to note that many of the UK citizens who have gone to Dignitas would not qualify for an assisted death if it was only permitted in the UK for patients with a prognosis of less than six months. It is clearly cruel and perverse to argue that you can have an assisted death if you are going to suffer for less than six months, whereas if you will suffer intractably for more than six months it is not permitted.

This report by the Assisted Dying Coalition shows how assisted dying in Switzerland is both humane and well-regulated. Reform of the law in the UK is long overdue.

Dr Henry Marsh

**Neurosurgeon and Author** 

## Introduction

The Assisted Dying Coalition (ADC) is the UK and Crown Dependencies coalition of organisations working in favour of legal recognition of the right to die for individuals who have a clear and settled wish to end their life and who are terminally ill or facing incurable suffering.

Founded in 2019 the coalition has written this report to highlight the true inadequacy and disparity of the broken UK assisted dying laws.



### Switzerland's assisted dying law

Switzerland has the world's longest-standing assisted dying law. The core of its legal framework permits (physician-supported) assisted dying, which is open to both Swiss and non-residents. It is one of the briefest of any jurisdiction.

#### Article 115 of the Swiss Criminal Code states:

Inciting and assisting suicide: Any person who for selfish motives incites or assists another to commit or attempt to commit suicide shall, if that other person thereafter commits or attempts to commit suicide, be liable to a custodial sentence not exceeding five years or to a monetary penalty.

This law led to the creation of non-profit assisted dying organisations in the 1980s. The most famous of these organisations is "Dignitas – To live with dignity – To die with dignity" (abbreviated: 'Dignitas'), which was founded in 1998. However, there are now other organisations that accept international residents. These non-profit organisations are highly scrutinised by domestic guidelines, regulations and the Swiss Authorities.

By law, each assisted death must be reported to the Swiss authorities, with the State Prosecution Service conducting an investigation. Only if all legal provisions are satisfied will the case be closed.

Furthermore, due to allowing non-residents to use the service, many international jurisdictions have researched and scrutinised the service. Dignitas is known to have contributed to numerous parliamentary inquiries and court proceedings, which is in line with their aim to make it unnecessary for any "foreigner" to use their centre, but rather have the choice of "the last human right" as they call it at home.

The cost of using these assisted dying centres can surpass £15,000 when transport, accommodation, expenses and assessments are factored in. Even though the centres can offer reduced fees and even waive fees entirely, the costs of going to Switzerland are considerable, especially for individuals who may already be immobilised, such as those suffering from motor neurone disease in an advanced stage.

### **UK assisted dying laws**

In England, Wales and Northern Ireland, assisted dying is illegal and punishable by up to 14 years in prison. The law states:

A person ("D") commits an offence if-

- (a) D does an act capable of encouraging or assisting the suicide or attempted suicide of another person, and
- (b) D's act was intended to encourage or assist suicide or an attempt at suicide.

An offence under this section is triable on indictment and a person convicted of such an offence is liable to imprisonment for a term not exceeding 14 years.

There is no specific crime of assisting a suicide in Scotland. But it is possible that helping a person to die could lead to prosecution for murder, culpable homicide or reckless endangerment.

Prosecutions for people in the UK who assist or encourage a suicide remain low, and cases like these rarely make it to a trial. However, there have been numerous cases of police investigations against families and friends who compassionately support loved ones to travel for assisted dying to Switzerland.

The investigations alone cause considerable stress and harm to the family members, loved ones and other individuals involved. We are aware of several instances of this, such as the case of Sue Lawford, who was arrested at 5 a.m., kept in a police cell for 16 hours and investigated for six months for accompanying someone abroad.

These investigations punish compassionate family members and loved ones who are only acting on the instructions and best interests of the people they care for.

In 2009, a woman with Multiple Sclerosis called Debbie Purdy, wanted to end her life in Switzerland and wanted to know if her partner would be prosecuted for accompanying her. The judges said that the law was not clear enough about when people would be prosecuted for encouraging or assisting suicide. They ordered the Director of Public Prosecutions (DPP), who at the time was Keir Starmer, to produce guidance on what makes a prosecution more or less likely.

We are not aware of anyone having been prosecuted for accompanying someone to Switzerland. The Crown Prosecution Service appears to close all cases eventually under the notion of "no public interest to prosecute".

# Summary

- There is an increase in UK residents using assisted dying services abroad. This increase will only continue in the absence of a compassionate UK assisted dying law.
- Richer and more affluent local authorities see high rates of individuals going abroad. Counties
  that are also further from an airport, meaning travel is significantly more difficult and expensive,
  often see fewer assisted deaths.
- Data on the types of cases that go abroad shows that many suffer from neuro-degenerative conditions. Some of them would not yet be classed as terminally ill or have less than six months left to live, showing that any law in the UK must ensure that eligibility criteria are based on suffering, not months left to live.

#### Nathan Stilwell, Secretariat for the ADC said:

"This report clearly shows that the UK's assisted dying law is broken, brutal and barbaric. We must stop exporting compassion to Switzerland and give choice, freedom and dignity to the people in this country who are suffering.

Having a postcode lottery to end suffering, and an unequal system where only the rich and physically able can take advantage, is absolutely wrong. 31 jurisdictions around the world, accessible to over 400 million people, prove that compassionate options are available.

Adults of sound mind, who are intolerably suffering from a physical, incurable condition deserve the freedom and right to have a dignified end-of-life choice on their own terms."

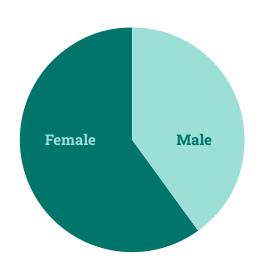
## Dignitas Data on UK and Crown Dependency citizens accessing an assisted death

The following data is only from Dignitas and does not include data from other assisted dying centres in Switzerland, or other British citizens who are residents of other jurisdictions with assisted dying laws.

#### Gender Breakdown

	Male	Female
Number of assisted deaths	218	336
Percentage of total cases	40%	60%

<sup>\*</sup>November 2002 to August 2023



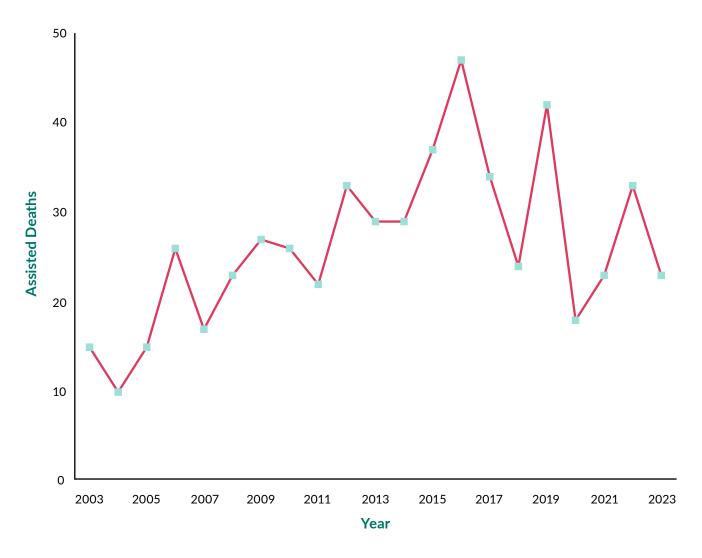
Currently, more UK women are using assisted dying abroad than men. The same applies for assisted dying cases of Swiss residents. This could be for a myriad of reasons, including the support needed to go abroad.

For comparison: In the Netherlands, in 2022 the ratio was almost equal, with 4412 men using the service (50.6%) compared to 4,308 women (49.4%). In 2021, across Canada, a greater proportion of men (52.3%) than women (47.7%) received an assisted death.

### **Increase in cases**

Assisted deaths of UK residents at Dignitas peaked in 2016 with 47 assistances, closely followed by 2019 with 42. There were 55% more assisted deaths in 2019 compared to 2009 and the trend of assisted death increasing may have continued if COVID-19 travel restrictions had not made travelling for an assisted death considerably more difficult.

#### **UK Dignitas Assisted Deaths**

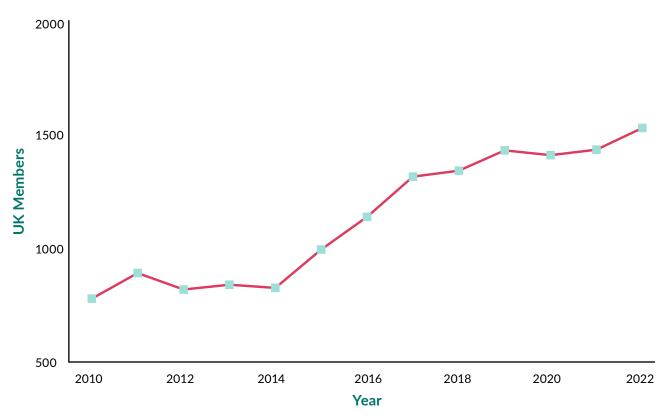


There is an average percentage increase year on year of 9%.

## **Increase in UK members of Dignitas**

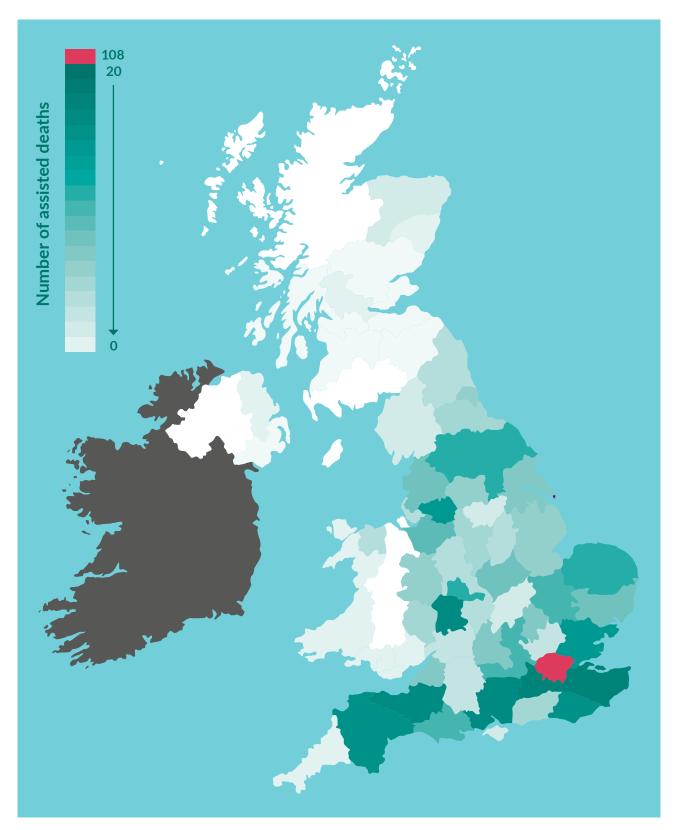
Year	UK Members	Difference
2022	1528	95
2021	1433	24
2020	1409	-21
2019	1430	89
2018	1341	26
2017	1315	176
2016	1139	143
2015	996	168
2014	828	-14
2013	842	21
2012	821	-72
2011	893	112
2010	781	

#### **UK Members vs Year**



### Postcode breakdown

A very clear trend is shown in the breakdown of Dignitas deaths by postcode.



Firstly, it is clear that an overwhelming number of people who travel to Dignitas are London residents. A large proportion of all people who have ever gone to Dignitas are from the south of England. Furthermore, eight out of the ten counties with the highest rates are in the south.

County	Assisted deaths
Greater London	108
Kent	20
Surrey	20
Hampshire	19
Devon	18
East Sussex	18
Essex	16
Greater Manchester	16
Somerset	15
Norfolk	12

<sup>\*</sup>November 2002 to August 2023

34 counties did not report an assisted death at Dignitas. They are:

Aberdeen City, Blaenau Gwent, Clackmannanshire, County Armagh, County Fermanagh, County Londonderry, County Tyrone, Dumfries and Galloway, Dundee, East Dunbartonshire, Falkirk, Flintshire, Highland, Inverclyde, Merthyr Tydfil, Middlesex, Moray, Neath Port Talbot, Newport, Newport City, North Ayrshire, North Lanarkshire, Orkney, Powys, Rhondda Cynon Taff, Rutland, Shetland Isles, South Ayrshire, South Lanarkshire, Torfaen, West Dunbartonshire, West Lothian, Western Isles and Wrexham.

# **Analysis**

A possible reason London and the south of England would see higher rates of people travelling to Dignitas is the cost and difficulty of travel.

Statistics on Gross Domestic Product (GDP) by region, London is the richest region of the UK, with a GDP of 496.4 billion British pounds in 2021.¹ GDPs of local authorities by the Office National Statistics (ONS) show similar results, with four London boroughs topping the richest local authorities.² According to the ONS data Manchester is the 7th richest local authority and it is the most northern county with the highest rates of people using Dignitas' services.

Paying for the service isn't the only issue, many people will struggle to go abroad. People who are going abroad for an assisted death are either terminally ill or suffering intolerably. Travelling for these people is incredibly difficult and it forces them to have an assisted death earlier than they would like, because they would need to travel while they are still capable of doing so. London is incredibly well connected, with several airports connected by public transport with good accessibility.

This would also explain why many of the counties without assisted deaths are rural counties, far away from airports, which makes travelling considerably harder. We have heard many stories of individuals needing to hire private ambulances or even private jets, in order to make it to Switzerland. Even this level of private transport may not be possible for severely immobilised patients.

8 million people in the UK (13.5%) did not have a passport in 2021.<sup>3</sup> No one in the county of Powys had an assisted death at Dignitas and Powys is one of the counties with the least levels of passport ownership - 22% of people in Powys don't own a passport. Only 2 people from Cornwall had an assisted death at Dignitas, and 21.5% of people in Cornwall don't own a passport.

Population size also accounts for a massive role in these figures. A key driver in the disparity could also be the large differences in population size. The data set of assisted deaths is small by comparison. Further analysis and research would be needed to make clearer conclusions.

<sup>1</sup> Statista, Gross domestic product of the United Kingdom in 2021, by region, D. Clark, Jun 2, 2023 https://www.statista.com/statistics/1004135/uk-gdp-by-region/

<sup>2</sup> Office of National Statistics, Regional gross domestic product: local authorities, 25 April 2023 https://www.ons.gov.uk/economy/grossdomesticproductgdp/datasets/regionalgrossdomesticproductlocalauthorities

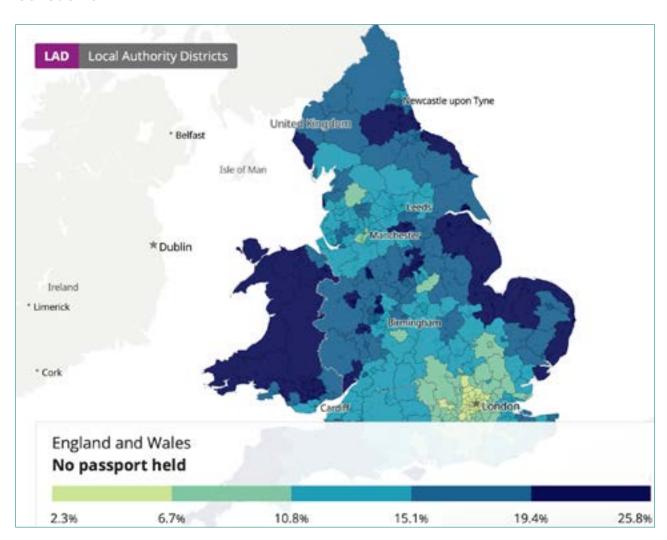
<sup>3</sup> Office for National Statistics (ONS) International migration, England and Wales: Census 2021 2 November 2022

In addition to population size, many other factors play a part in individuals' decision to go to Dignitas. Individuals may move to London for healthcare opportunities or treatment before they later travel to Switzerland. Awareness of Swiss centres and being in proximity or knowing someone who has gone abroad for an assisted death may play a factor as well. There are many nuances to the data that affect making a clear analysis of causation.

However, one clear conclusion is that there are massive disparities between the people who are using Dignitas' services. The status quo is unjust and unfair. Forcing anyone to leave their home, their family and their country in the first place is barbaric.

The current legal status of assisted dying in the UK is not only inadequate and incoherent as The Commission on Assisted Dying put in their 2012 report. In fact, it violates the basic human freedom and right to decide the time and manner of one's own end in life and it discriminates against people who are less able and fortunate than those who can still "escape to Switzerland".

#### Office for National Statistics (ONS) Passports held, England and Wales: Census 2021



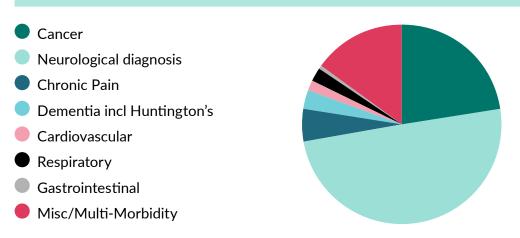
# Diagnosis breakdown

In addition to the location data of the members of Dignitas, we were able to receive data from two other Swiss assisted dying organisations. Analysis was carried out by Marie-Claire Hopwood, palliative care consultant, Dr Graham Winyard, retired public health physician and former Medical Director of the NHS, and Dr Colin Brewer, retired psychiatrist and former director of Westminster Hospital's community alcoholism treatment service.

They analysed the diagnoses of UK residents who had an assisted death during periods between 2005 and 2022<sup>4</sup> at all three of the Swiss organisations that provide this service to non-residents of Switzerland.

Table 1: Diagnoses of UK Residents receiving an assisted death in Switzerland

Diagnosis	Deaths	%
Cancer	92	22.7%
Neurological diagnosis	201	49.6%
Chronic Pain	21	5.2%
Dementia incl Huntington's	13	3.2%
Cardiovascular	7	1.7%
Respiratory	8	2%
Gastrointestinal	3	0.7%
Misc/Multi-Morbidity	60	14.8%
Total	405	100%



<sup>4</sup> Note this is a shorter range than included in the data on location.

The most striking finding is the preponderance of UK patients (49.6%) with slowly progressive or non-progressive neurological conditions. This is in marked contrast to the US state of Oregon, for example, where cancer is by far the most common diagnosis. The 'miscellaneous' category is largely composed of patients (average age 85) with multiple degenerative pathologies of late life.

Table 2: UK Residents with neurological diagnoses receiving an assisted death in Switzerland

	UK Residents	
	Nos	% of all patients
Motor neurone disease	79	19.5
Parkinsons/ Multiple system atrophy (MSA)	15	3.7
Multiple Sclerosis	63	15.5
Spinal problems/stenosis	9	2.2
Progressive Supranuclear Palsy	7	1.7
Paralysis*	11	2.7
Ataxia	3	0.7
Locked in syndrome	1	0.5
Other	13	3.4
Total	201	49.6

<sup>\*</sup> incl tetraplegia and status after stroke

## Conclusions

Neuro-degenerative conditions make up the majority of individuals who travel to Switzerland for an assisted death. This is an important factor for politicians in the UK.

Every law that has been proposed in the UK so far has been based on the 'Oregon Model', the legislation introduced by the US state of Oregon in 1997. Through this model, only people with a terminal illness who have six months left to live or less are eligible to have an assisted death.

However, this study shows that more than half the patients going to Switzerland would not be expected to die from their condition within six months or a year, and would be clearly ineligible under the same model that is used in Oregon, or UK-based assisted death legislation stipulating a requirement for a terminal illness diagnosis where death is expected within six-months. (This would have also been true for the two individuals, Tony Nicklinson and Paul Lamb, who fought for the right to receive assistance for their self-determined death through the courts and whose Supreme Court challenges remain landmark cases.)

The Assisted Dying Coalition urges all UK and Crown Dependency parliaments to introduce the most compassionate law possible. That law should be based on reducing suffering, not an estimate of how long people have left to live.

We recommend that the UK legislation on assisted dying should be based on the following:

Any adult of sound mind who is intolerably suffering from an incurable, physical condition and has a clear and settled wish to die should have the option of an assisted death.

The Assisted Dying Coalition continues to highlight the immense suffering being felt by families across the UK. Every day, families and individuals suffer unnecessarily as a result of our outdated and broken laws on assisted dying. This data from Dignitas confirms that not only are more Brits resorting to travelling abroad to end their lives, but the current set-up is unequal and immoral. The law needs to change.



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### Members of the assisted dying coalition:

- End of Life Choices Jersey
- Friends at the End
- Humanist Society Scotland
- Humanists UK
- My Death, My Decision
- My Death, My Decision Isle of Man











