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Assisted dying: Campaigners leave Dignity in Dying over law change policy only for people with less than six months to live

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Several Welsh campaigners for assisted dying have left the organisation Dignity in Dying because they disagree with its policy of restricting a change in the law to people with no more than six months to live.

Miriam Day, orthopaedic surgeon and specialist in musculoskeletal trauma at Cwm Taf Morgannwg University Health Board, was until recently the key campaigner in Cardiff's Dignity in Dying group. She and nine others, of 12 active members, decided to leave Dignity in Dying after learning that its policy would not help people such as Paul Lamb, a man paralysed from the neck down. They have now joined the group My Death, My Decision (MDMD), which is calling for a broader change to the law to include terminally ill people and those with incurable suffering.

Day told *The BMJ*, "Dignity in Dying never made their policy transparent to me—you had to really search in the small print to find that they are only campaigning to change the law for people with a prognosis of six months or less left to live.

"Such a policy is discriminatory, as it would exclude people facing years of constant and unbearable suffering. A lot of the people with neurodegenerative disorders, such as those used by Dignity in Dying in their campaigning, wouldn't actually be able to access the law the organisation is campaigning for."

Two models

There are two models of assisted dying around the world. Help to die is permitted for terminally ill and incurably suffering people in Canada, Belgium, Italy, Germany, Luxembourg, and the Netherlands. The other model—adopted in some US states and the Australian state of Victoria—allows assisted dying only for terminally ill people with a condition likely to cause death in six months or less. Last week New Zealanders voted overwhelmingly in a referendum for a law legalising assisted dying for mentally competent adults who have a terminal illness likely to cause death within six months and are experiencing "unbearable suffering."¹

However, Day argues that prognosis is very hard to predict, explaining that "it puts the power back with the doctors when it should be about patient autonomy."

Sarah Wootton, chief executive of Dignity in Dying, told *The BMJ*, "We are proud to campaign for a strongly safeguarded law that has been demonstrated to work for more than two decades in the US, has been the model for legislative change in Australia and New Zealand, and is currently under consideration in Ireland."

She added, "Dignity in Dying has a 50 strong network of local volunteer groups. A small number of our Cardiff group supporters have left the organisation due to a difference of view over our policy, which is integral to our campaign. The vast majority of our members agree with Dignity in Dying's stance, which we have held since our incorporation, to campaign to allow people who are terminally ill and mentally competent the choice of an assisted death.

"Over the summer we consulted our members on our modernised articles of association, which are explicit about our campaign aims to change the law for terminally ill, mentally competent adults. The revised articles received 98% support from our membership."

Doctors' views

A large survey of UK doctors' opinion carried out recently by the BMA found that half of doctors were personally in favour of a change in the law, with 39% opposed.² When asked whether the BMA, which currently opposes assisted dying, should support a change, 40% said that it should, while 21% favoured a neutral position and 33% said that it should remain opposed.

Colin Brewer, a writer and retired psychiatrist and addiction specialist who is a member of both campaigning organisations, told *The BMJ*, "Copying an Oregon model exclusively focused on terminal illness with a six month prognosis is inhumane. People with motor neurone disease can take several years to die, and it can be extremely unpleasant. Also, dementia is now our commonest cause of death, and quite a few people with early Alzheimer's don't want it to get to an advanced state involving years of increasing loss of autonomy and dignity and much suffering for patients and for their families."

He added, "Palliative care is full of people with strong religious views, and consultants who support reform are afraid to speak out for fear of being ostracised by colleagues."

Iain Chalmers, a retired health services researcher, was a patron of Dignity in Dying but left it to join MDMD because he also disagreed with the six month time limit. "It's arbitrary and can't be justified," he said. "It excludes people with longstanding disabling neurological conditions who won't necessarily die in the next six months but wish to be relieved of life.

"There has been a dogged refusal by Dignity in Dying to discuss its six month criterion."

- 1 Dyer C. New Zealanders vote to legalise assisted dying for terminally ill adults. *BMJ* 2020;371:m4239. doi: 10.1136/bmj.m4239 pmid: 33127825
- 2 Torjesen I. BMA should drop its opposition to assisting dying, say members in landmark poll. *BMJ* 2020;371:m3936. doi: 10.1136/bmj.m3936 pmid: 33037048