

Nurse joins fight for dignified death

A terminally ill woman who knows what awaits her is supporting a bid to change the law, Greg Hurst reports

Within days of being told that she had motor neurone disease, Alison Pickard had a harrowing dream. As a nurse practitioner she knew what happened to people with degenerative neurological conditions. Many times she had sat at the bedside of such patients and watched them suffer. In her sleep her mind fast-forwarded to the fate that she knew awaited her.

"Very early on after I was diagnosed, within days, I vividly remember dreaming — a nightmare really — that I couldn't move and I couldn't speak and couldn't breathe and I couldn't tell anybody," she says.

Mrs Pickard, 60, from Retford, Nottinghamshire, is among a series of witnesses who have given evidence to support a legal case to be heard in the

High Court this week challenging the ban on assisted suicide. She and another witness will describe the symptoms of progressive muscle wastage that are part of motor neurone disease, and others will give testimony on behalf of wives, brothers and daughters with terminal cancer.

The case has been brought by Noel Conway, 67, a retired lecturer from Shropshire with motor neurone disease who says that the Suicide Act 1961, which makes it an offence to assist in a suicide — with a maximum jail term of 14 years — breaches human rights law.

Mr Conway was refused permission to apply for a judicial review in March but went to the Court of Appeal, which overturned the ruling in April, allowing him to proceed.

Some legal experts and campaigners expect the case to go to the Supreme Court and put pressure on parliament to reconsider the law on assisted dying.

By submitting evidence from other witnesses, he will argue that a narrow category of people with similar terminal illnesses, if they are adults with mental capacity to decide for themselves, should if they have six months or

less to live, be allowed to have assistance to bring about their death.

Mrs Pickard, who retired this year, has lost the use of her left hand and arm and uses a mobility scooter. Although her condition has progressed more slowly, she knows what awaits her.

"With motor neurone disease unless you are lucky enough to die of a stroke or something incidentally in the process of the disease, end of life with motor neurone disease means you can't speak, you can't swallow, you can't breathe, you can't move. What can be worse than that?" she says. "If you continue right until the end, that's what's waiting for you. Basically and fundamentally I don't want that for me and, more importantly, I don't want my nearest and dearest to have to watch me going through that, because it's not a worthwhile or a productive experience for anybody. It's just horrible."

She would not, she says, go to a Swiss clinic on principle; she wants the right to die at home.

Provisionally she has decided on an advanced directive that she should not be resuscitated and thinks that she would refuse tube feeding if she

couldn't swallow and would also reject an oxygen mask, known as non-invasive ventilation.

The second of Mr Conway's witnesses is Joy Brighton, 71, who used to run her husband's estate management and property business and breed and show bulldogs. She had never been ill before motor neurone disease was diagnosed in late 2013. She has lost her mobility, needs a hoist to move and is fed through a tube into her stomach. She has also lost her speech.

Mrs Brighton plans to travel to Switzerland, perhaps within months, to end her life. To be interviewed by *The Times*, she clicks on a computer mouse on her lap and types — one letter at a time — on a tablet on a table in front of her at the bungalow in

David Brighton with Joy, who has lost her speech



Taunton, Somerset she shares with her husband David and a carer.

At the end of each short sentence she presses a button to turn the script in to speech, although, frustratingly, several became gobbledygook.

Asked when she would end her life, there is a long pause as she types: "I will know when it is time."

Mrs Brighton, who has two sons and a daughter, taps out: "It makes me angry that I can't be with my loved ones when I die." She and her husband are churchgoers; she used to do the

flower arrangements and latterly has directed her carer in doing so. How does she reconcile her decision with her faith? "I think God does not want me to suffer," she taps slowly. Her mouth hangs open, beyond her control, but her eyes blaze as she scrolls the mouse with her rigid fingers.