

Fiona MacKinnon

Dystonia on a small island



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Fiona MacKinnon has hemidystonia and also experiences dystonic storms (see the Q&A on page 9 for more information on dystonic storms). Managing her dystonia is complicated because she lives on the Isle of Tiree in the Hebrides. She has worked closely with our advocacy service to get the support she needs. Here's her story:

"My dystonia appeared when I was 12 starting with cramps in my right foot. The cramps

established themselves and the dystonia spread up the right side of my body. I also have dystonic storms and once I had to be carried off the school bus because I could not move. I was told not to come back to school for 6 months! For fifteen years after my dystonia developed, the doctors assumed the symptoms were caused by schizophrenia.

I live on the isle of Tiree which only has 700 inhabitants. It is the sunniest and windiest place in the UK. My doctor told me there are 6 people with dystonia living on the island which means the proportion of people with dystonia on Tiree is one of the highest of anywhere in the UK.

When I was 27 my mother saw a TV programme about dystonia while she was lighting the fire and was convinced that this was what I had. We contacted the Dystonia Society for information and, as a result, my doctor sent me to Glasgow to the neurology department at the Southern General hospital. While I was there they asked me to go downstairs in a lift to see some neurologists and I had to ask them how to do it as I had never been in a lift before! They told me my diagnosis was hemidystonia.

The dystonic storms are a problem for me. My croft is quarter of a mile from the nearest house and when they strike I cannot move to sound the alarm. The council have installed an automated alarm which should detect when I have a dystonic storm but either it doesn't work

or it sounds every 30 minutes whether I'm having a storm or not! Also, because many people on the island are elderly it is difficult to organise carers I need.

Sometimes, those responsible for my care have not always known enough about dystonia. For instance one medical report said I had 'dystonia caused by anxiety' – and this was nearly twenty years after I had been diagnosed with a neurological condition!

The help I have received from Angie at the Dystonia Society Advocacy Service has been fantastic. She's written letters to support services explaining the condition – and they've made a huge difference. The quality of care I receive has improved a lot and no-one talks about anxiety as a cause now. I keep telling support services that I want to rely on them as little as possible – for four years after my mother died I managed independently with local carers.

The Dystonia Society Advocacy Project is such a worthwhile project. I'm quite a strong personality and am used to arguing for what I need. But I worry about others who may not be able to fight to get the right care – so it's really important the Dystonia Society is there to help."



● Fiona's watercolour 'Boat at Scarinish Beach'

Hemidystonia refers to the situation where dystonia only affects one side of the body. Typically this involves the arm and leg. This form is usually the result of injury or problem with the basal ganglia on the opposite side of the brain to the dystonia. One typical cause is stroke but there are other causes.