

Dear Friend,

I'm writing to you this Christmas to tell you about the work of my team – the Advocacy Service at Muscular Dystrophy UK – and the impact kind support such as yours enables us to have on families like Katherine's.



In the course of my work, I talk to a great many individuals and families affected by muscle-wasting conditions. Everyone's circumstances are unique, but most often people get in touch with us because they are feeling frustrated and overwhelmed and in need of practical and emotional support.

For families like Katherine's, what often proves to be most exhausting is the sheer complexity of the situation they're facing. In addition to coming to terms with a muscle-wasting condition diagnosis, they may have to deal with many different people, ranging from their medical team to their local council to the Department for Work and Pensions. Sometimes communication can be challenging so families often find they have to go back and forth, repeating their story to different people in the same department, or being put through various switchboards trying to get the answers they need. This can all be mentally and physically exhausting.

This is where my team and I step in. People have enough in their lives to manage and deal with – so we get involved to try to take some of the stress away and support them to move things forward.

Because we cover the whole of the UK, and we're familiar with many of the processes, we know when things are moving too

slowly, or when an unfair decision has been made. This means we can equip families with knowledge – letting them know what options are available to them to be able to access what they need.

By providing this broad range of expert support, we help move things forward. We liaise between all the different organisations involved in, for example, providing home adaptations, so a mum like Katherine can focus on what's most important – her family.

Muscle-wasting conditions are very rare and complex and often unique to the person or the child. We do a lot of work with other agencies to help them understand how the needs of a child like Joseph are likely to change as his condition progresses. They may not know that an assessment done today will be out of date in a few years' or even months' time. We want to help families focus on forward planning, to make sure whatever is put in place now is going to continue to meet the person's needs in the future.

When you have a child with a muscle-wasting condition, it can be terribly lonely and isolating – as if you're fighting all these battles on your own. My team provides a level of support that these families may not have elsewhere. Right now, there are families all across the country who will need someone to stand with them and advocate for them in the year ahead. Please give what you can this Christmas so that we can keep doing this life-changing work. Thank you.



Jackie Munro

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Regional Information, Advocacy and Support Manager