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Mr Darryn Gibson
CEO
Healthcare at Home
107 Station St
Burton upon Trent
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10th November 2020

Dear Mr Gibson

The Haemophilia Society exists to be the voice of people with bleeding disorders across the UK. It is with the patients' voice in mind that as Chairman and CEO we are writing to convey our outrage on behalf of people with Haemophilia and their families at the unacceptable breakdown of your delivery of essential medications over recent weeks. At any time this would be unacceptable, but in the shadow of the global pandemic the recent breakdown is simply unforgivable.

We understand this most recent breakdown is due to the problems with a move to a new Microsoft platform. We would request you publish the risk register your organisation put in place prior to migrate to the new platform to mitigate against the disaster you have overseen, enabling our members and ourselves to understand why we have reached the situation we are in. Sadly, this breakdown in services is part of a pattern which we have observed in recent years from Health Care at home that is being repeated time and again and cannot solely be blamed on recent technology.

Over recent months, we have continuously received complaints from highly distressed, frustrated and frightened patients or their parents. Repeated failures include:

- essential medications not delivered on scheduled dates;
- delivered medications stored at incorrect temperatures so are useless;
- basic equipment such as wipes and sterile gloves out of stock or delivered but out of date;
- deliveries missing items or with incorrect items;
- helplines staffed by people with no training on Haemophilia issues leading to further delays and frustrations.

One consequence of essential medication not being delivered on scheduled dates is that several patients have been left with little or no medication whatsoever to treat their bleeding disorder. When well-managed, bleeding disorders are relatively well tolerated conditions. When left with no treatment, at best, patients and families are put at risk by having to leave home to obtain treatment,

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exposing them unnecessarily to contracting Covid-19. At worst, it leaves patients dangerously exposed to internal bleeding with no or little treatment available at home. If left untreated or treated insufficiently, inter-cranial bleeds can quickly become deadly.

We have also been told of parents driving hundreds of miles in desperation to obtain medication for their children. Many have now reached a stage of accepting that there is no patient choice at suffering from a consistently below par service. On their behalf, we refuse to accept that this must be the future for them.

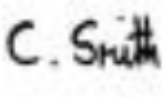
We believe that a series of urgent improvement measures must be put in place, including:

- An immediate increase in staffing or confirmation that sufficient staff are in place to manage the demands of patients with bleeding disorders;
- A training programme for all staff involved in Haemophilia support;
- An immediate investigation as to what went wrong and why, which is then published for our community to understand why they have been put in such a perilous position

As CEO of Health Care at Home we feel you should also personally apologise by letter to everyone who has been let down by your organisation and acknowledge the anxiety and frustration caused.

We look forward to receiving your response to all the issues raised.

Yours sincerely



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