

**Cherry**

Cherry is 20 years old, lives in London and has been ill with ME for nearly 5 years since contracting Glandular Fever in June 2013 when she was 15 years old. Glandular Fever (Epstein Barr Virus) is a common viral trigger for ME.

Cherry’s current situation is desperate as she is at the most severe end of the ME / CFS disability scale. There is no available prognosis as to if, when, or to what degree she might recover.

Cherry is totally bedbound due to extreme fatigue.

She is highly sensitive to light and sound, so spends her time in bed in a darkened room wearing noise cancelling ear plugs / ear defenders and eye patches.

She is unable to get out of bed so requires complete assistance with her personal care needs.

Cherry is unable to swallow reliably so is dependent on naso-jejunal tube feeding for all her nutrition.

Cherry has a terrible quality of life. She is too ill to listen to the radio or music, read, watch TV, use the computer, talk or text on the phone, or see friends.

All she can do is lie in bed, waiting, hoping and praying that she might start to feel a little better.

When well, Cherry’s main interests are art, politics, current affairs, Spanish language and culture, film, theatre, running, walking / hiking, and seeing and socialising with friends. She is unable to pursue any of these.

Cherry has now missed the last four years of her education. She was too ill to attend 6thform, go to university or do remote learning from home.  This is a heavy blow as Cherry is academically very bright and always loved study.

She has been unable to attend any family events for the past 3 years.

Cherry’s father died in February last year (2017) which caused massive grief, adding an unbearable level of psychological distress on top of her chronic and severe physical illness.

She recently endured an 11-week hospital admission as she had become so ill with ME that she lost the ability to swallow and needed to have a feeding tube inserted.

 It is very difficult for Cherry to remain hopeful for a recovery due to the extreme severity of her symptoms.

Cherry is only 20 years old and deserves a chance for recovery and a reasonable future.

**Further detail**

Cherry was diagnosed with CFS / ME in April 2014 by the CFS Outpatients’ Clinic at a major London hospital. At that time she was attending school part time. She started NICE recommended treatment, Graded Exercise Therapy (GET), in May 2014 but this did not prove effective and by November was house bound and mostly bed bound.  In early 2015 she did the Lightning Process (recommended as an alternative approach to recovery from ME). This initially brought some improvement, but ultimately caused a ‘crash’ and worsened her condition. By autumn 2015 she was again housebound. In 2016 she tried another form of psychological-based treatment for ME but again this did not help Cherry to recover. This was highly distressing and demoralising, as her wholehearted efforts towards recovery over a two –year period had resulted in no improvement in her health, and in fact increasing deterioration.

To add to her challenges, Cherry’s father died in February last year (2017), which caused massive grief, adding an unbearable level of psychological distress on top of her chronic and severe physical illness. This was compounded as she was too ill to access telephone-based grief counselling and there was no appropriate home-visiting psychological support available. Over the following months Cherry struggled more and more to have the energy to eat, until she ended up as an emergency admission to her local hospital on 31 October, due to malnutrition and dehydration caused by losing the ability to swallow. Sadly this is a fairly common experience for people with very severe ME who may need to be tube fed for months or years of their illness.

Cherry was discharged home after 11 weeks on 18 January with a naso-jejunal feeding tube.  Although necessary, the hospital admission was extremely difficult and stressful as the doctors treating Cherry had no previous experience of treating someone with severe ME, most of them had little understanding of the illness and its symptoms, and some had dangerously outdated and inappropriate views.

On discharge from hospital Cherry has been given some support via her borough’s Adult Social Care. Four x 30 minutes per day for her personal care needs. Cherry however needs 24 / 7 care as she is too vulnerable to be left alone so her grandparents look after her during the working week whilst her mother is at work.

There are no home-based treatment options for ME available to Cherry via the NHS in her home borough. As she is totally bedbound and housebound, she is too ill to access the only service provided by the local Clinical Commissioning Group – a hospital-based outpatients’ clinic.

Cherry’s GP is doing what she can to support Cherry in the total absence of any NHS consultant-led advice or treatment.

Cherry’s mother is searching relentlessly for treatments or practitioners that might be able to help Cherry.