

**P-05-754 Lack of support for children with disabilities at crisis –
Correspondence from the petitioner to the Committee, 23.01.18**

I'd like to thank the committee for the time you have given, I am truly grateful. I am also thankful for Vaughan Gethins response regarding the petition. However we as a family of a child in 'great' need are still in the same position almost a year later prior to the petition. I can honestly say we hold back now when Thomas becomes more unwell – 'hits crisis'. We try to manage the best we can, which in return results in our other children being late for school, missing out on days out, parties, my husband missing work, and myself suffering with anxiety and having to take time off work as a registered Nurse, working for the NHS, due to not being able to cope with the lack of support for Thomas. We are so drained with the constant battle and just fight every day to help Thomas get through the day as comfortable as possible. I can't help but think about other children similar to Thomas who do not have the support from direct family, as I have stressed even with the support we give Thomas, it is 'lonely and scary'.

I take on board that Vaughan Gethin has stated in the latest response that there will be improvements and funding within the services, however my worry is what is available now for children like Thomas? Improvements and funding is great, but there needs to be services available now, these children need it now! A few months, years time is not good enough. We are living in these circumstances this minute, today, now. Tomorrow is not going to help a child who is in need today.

Kind regards,

Rebecca Weale