

Personal Healthcare Budgets (PHB) – Paul’s story

“Prior to having a Personal Healthcare Budget (PHB), care was provided by a local office of a national company. Despite being as flexible as possible with regard to creating a care plan with them, due to my communication difficulties there were certain issues my wife and I felt were critical (carer consistency mainly), and we were assured this was understood and other than in emergencies this could be accommodated.

Very quickly it became apparent that they could not provide this service with my wife counting 38 different carers in a 5-week period. Even escalating our complaints to a regional and national level the service did not improve. There were a few issues but after being attended too by a lady who I believed to be still drunk from the night before, I decided to investigate if it could be done differently. It became apparent very quickly that even a change of company would only go a certain way in resolving our issues. By opening up our home we didn’t know from one day to the next who we would have causing anxiety over security, the carers worked to their own mandates with no acknowledgement of our needs, and with what can only be described as false promises by the company it created circumstances that caused my wife and I a huge amount of stress and anxiety on top of dealing with my condition. It was horrible.

We went through the PHB application process with a lady called Pat from Continuing Health Care who genuinely seemed to understand not only the physical challenges I now faced but also the mental effect. Even now some of her advice is invaluable. With a PHB I was able to vet and employ my own care team. Their duties are set according to my needs on a daily basis. Because they are employed by me, any issues I (or even they) have can be dealt with immediately so there is no opportunity for issues to escalate. We also now know who will be in our home and when, I have been able to ensure my team can use my communication board so I can make them understand me more.

I don’t doubt that I have been very lucky to have the team I have, and we have had bumps in the road, but because I have the ability to react effectively when that happens, I have managed to keep a consistency and quality of care that is suitable.

This ability and effect is also true in other areas. With the best will in the world it is not possible to anticipate every need that I may have, it is not until you are living life in the circumstances that you become aware of problems. Having the ability to instantly deal with the problem and having the flexibility to overcome issues quickly and in a way that fits with my circumstances is a great help.

There is no doubt that I would give anything to have even a partial recovery, but as this seems unlikely I am having to adapt and almost learn again how to live. I really wish I didn’t need any help but I do. Compared to having no PHB the situation now is chalk and cheese. The stress of my care and overcoming challenges my circumstances present whilst not gone are just a fraction of what they were before and I honestly believe that has kept both my wife and I sane.

Having a PHB really works for me, it gives me the flexibility to deal with problems and overcome challenges myself and this prevents further deterioration and a reliance on already strained resources.”