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I have multiple sclerosis and have no use of any of my limbs. I have support which is mainly local authority funded, including a few hours of direct payment. I also have overnight stays funded by Independent Living Fund as I often have spasms and have to be repositioned in bed. I have, for the most part, a good care package. I have carers who come in during the day to help get me washed, dressed and fed.

However, we are coming into difficult times. Following the changes in legislation around the national living wage and employment law test cases about

sleepovers*, the cost of an overnight stay has gone up from £32.50 to £60 which is impossible for me to pay. I have approached the Independent Living Fund but they cannot fund it. I feel very vulnerable when I am in bed. During the day I can drive my wheelchair with my chin and have an environmental control box to operate my TV, computer and lights but at night I can't move myself at all.

I am now trying to see where I can go with the Independent Living Fund on this but the local authority has a duty of care.

Having sleepovers means that I can relax, rest and sleep well. This lets me operate well during the day and has a positive effect on my relationships, my voluntary work – all of my independence, really. Without sleepovers I would be frightened, I wouldn't sleep and I'd end up tired and upset.

Ideally, I would like to be able to pick my own team of staff but I can't see the council letting me do that. I need intimate, personal care and much as I know I need it done, I never like it. Continuity is so important in terms of the people who are delivering this kind of care and it makes life a lot better if it is someone with a bit of humour. If I could pick my own team and they remained constant I would be more relaxed and I could use my energy for things other than training and building relationships with new staff.

I also want to see more flexibility with my hours to support my voluntary work. I am on the board of two organisations, a housing association and a disabled people's organisation, and give talks to new local authority staff from a service user's point of view.

I asked for 5-10 hours a month of self-directed support so I can take a personal assistant to meetings with me and take notes, as I have a lot of papers to read. I was told this was neither "critical or essential" yet social care support is meant to help someone with doing work, paid or voluntary. Volunteering lets me make use of my lived experience to help others and I find doing this cathartic. It's good for the soul – I feel I'm contributing, it keeps the head active!

I have had three meetings with my social worker about having my package reassessed but eventually I was warned not to go ahead with a reassessment as my budget would be cut, without telling me why.

I have taken part in several consultations but in my opinion it's a tick box exercise so they can say they have consulted service users and nothing changes.

Having the right support allows me to live a life – get out and about, meet my friends, volunteer. I've got a purpose: I'm contributing to the life of my friends, family and community, and that gives me a feeling of self-worth.