

Eq. 359. Re "10/2/11"

1. Concerning your question 1, in my case it's all down to the medical conditions and disabilities causing pain, exhaustion, nausea, diarrhoea and constant infectious diseases. Before my condition deteriorated it was a diabolical struggle with work because there is no system whereby disabled people can contribute work tailor made to fit their ability and availability. This lack can only result in frustration, pressure, overload and breakdown and dissatisfaction for employers. At interview you have to prove you can do a job no ifs or buts. This can never work for significantly long term disabled people. They need work to fit them rather than having to shoe-horn themselves into an impossible situation which can lead only to failure.

2. Concerning your question 2, there should not be any means-testing introduced by this reform either directly or indirectly: claimants should be assessed on their health conditions and disabilities only. Otherwise to scrap the universality of this benefit would be grossly unfair to the claimant who has paid their dues into the social insurance system over decades of hard work only to realise in the time of their reduced ability that their past contribution is not acknowledged or valued by the state and that their financial thriftiness and prudence has, in retrospect, been unwise. This realisation would, in turn, lead to their anger, frustration and depression which would adversely affect the quality of their lives and aggravate their existing health conditions. It would also send a signal to others to fritter away everything so they can claim everything so encouraging a nation of wasters. Government thinks

work should pay. However claimants should not be assessed on or penalised for their savings because they represent past hard work and endeavour while they were still able to work and responsible financial management and funding of investments which help the economy.

3. Concerning your question 3, some of the extra costs of disability are transport, eg use of accessible taxis and contribution to the Taxicard Scheme, purchase and maintenance of a mobility scooter, the extra costs of having shopping delivered whether by a carer, neighbour, friend, supermarket home delivery services, or online purchases with their postage and packing costs made because a personal visit to shops is not manageable. Medication baths cost extra for water and heating it. Door entry systems and cordless phones around the house or alarm call systems all consume extra money from the disabled. I have to pay workmen to come and maintain my home which now includes all the small jobs I used to manage myself.

3. Concerning your question 4, I think that two-level support will be insufficiently flexible to be fair to claimants and will result in some deserving claimants being excluded from benefit.

4. Concerning your question 5, claimants with chronic and incurable such as cancers for which they have been assessed in the past and met the eligibility criteria should be given the peace and quiet they want and deserve and not hauled repeatedly over the assessment coals yet again by this change. Unless there are grounds to suspect fraudulent claims the new rules for claimants with existing conditions which have no end in sight during their remaining years should be excluded from this upheaval.

5. Concerning your question 7, variable medical conditions must be eligible for benefit because the patient cannot chip in an hour or two of paid work when they are having a good day or a good few hours. When claimants with serious conditions get a few good days they are hard pressed in trying to catch up with the domestic and administrative tasks required in every day living which piles up during the spells they are bed or armchair ridden or called away from home for inpatient or outpatient hospital treatment. It is sensible that claimants tackle their vital life support tasks when they are able as otherwise money would have to be found to pay outside people to come in to do it for them. When claimants are fully stretched coping with their disability and with the tasks of meeting their daily living needs it is folly to push them towards work and endless reassessments. All that achieves is greater administrative costs to the DWP, a complete breakdown of the claimant and so more strain on the NHS and other public services.

6. Concerning your question 8, claimants should be rewarded or compensated by the benefit for having to persevere with and rely on gadgets and equipment which they need to enable their everyday living and not penalised or lose benefit for the provision of aids or for using their initiative in obtaining their aids to living with disability. The benefit should be seen in part as a recognition or compensation from the state or society that acknowledges the claimant's additional disadvantage in relation to fitter people. Claimants should never be left in the position where they are forced to bear the full brunt of their health problems while finding themselves excluded from benefit because they have strived to cope by making use of equipment aids or have strived during their working lives to accumulate savings. That will cause self-destructive feelings of rejection, exclusion and unfairness. Claimants past work must be taken into account as much as current work. Past deductions through tax and insurance have been their contribution

into the welfare insurance system and people who have paid in expect to receive payments out when medically eligible.

I have had some equipment provided on loan from the local council social services community equipment service on the strength of the medical assessment but now seem to be increasingly denied help provided to others who are no more disabled because I refuse to submit to a means-test. I learned my lesson once when I filled in all the means-test part of the forms and was then denied the service on those grounds alone. The result was that I felt bitter because I have paid in for the service throughout my working life and am penalised for my financial prudence and not accumulating debt. I was offended that the result was I got nothing out of the application exercise other than an exacting paperwork task while the council got hold of and stored my very personal financial information which all the time I pay my council tax is none of their business. All vital medically assessed aids and care should be provided on the same basis as NHS services, free at the point of use, and funded from our expensive council tax and income tax contributions. Money can be saved for the purpose from that saved by scrapping the expensive mean-testing machinery and by controlling grossly wasteful expenditure on pet and trendy schemes such as the £3.2 just thrown away on an unnecessary high street reconstruction by London Borough of Sutton which 80% of residents have voted that they hate.

7. Concerning your question 9, the adverse and negative impact of assessments on claimants must be realised, addressed and minimised. It is unspeakably stressful and demeaning to be continually quizzed to justify your claim and becomes a terrible burden on top of the pressures of coping day to day with chronic incurable illness and disability. I have had on occasion to seek urgent medical assistance from uncontrollable anxiety symptoms when suddenly faced with yet another lengthy questionnaire booklet



to complete by a deadline with the warning that failure to manage this will result in sudden stoppage of payments. I plunged from enjoying a hard-won stabilised condition to a very ill patient within a day or two and having to focus on my illnesses, symptoms and disabilities again to fill in the pages brought me down further - a nightmare situation. It took considerable medical intervention time and money to get me back to where I was. I found it a very difficult and complex task to fit a proper representation of my difficult circumstance into the multitude of separate, narrowly-worded questions becoming tireder as the hours and days went by. There should always be a catch-all question with space and freedom to describe the detail of the daily struggles that have to be surmounted to live with and manage chronic illness and disability.

8. Concerning your question 10, unless the claimant is in institutional care it has to be said that they are the ones in the best position to provide a clear assessment of ability since they have to live in their body 24 hours a day while the GP and other professional may see them only for short periods of time and any one assessment in an unfamiliar assessment centre staffed by strangers to the claimant can easily produce distorted results for many reasons, eg the claimant's nervousness, lack of ability to represent their case, the time pressure on and experience and competence level of the examiner. Every available source of information should be used from medical summaries to witness statements from family, friends, neighbours. Claimants should have free access to an advocate to relieve or help them with the compilation of this evidence which presents a formidable task to many claimants. Maybe the health care professional involved in the suggestion for change should be charged to help with this.

9. Concerning your question 11, the face-to-face discussion with a healthcare professional can be very intimidating for a disabled

person who is convinced that the sole aim of the interview is to get them off benefit. I have heard from friends who have found in past DLA interviews they were in a hostile environment, had no rapport with the questioner, and sensed a dismissive, closed mind policy aimed at meeting reduction targets. The interviewer should make it clear that they are there to help the claimant and not to penalise them and maybe the claimant should be provided with an independent advocate or referee to invigilate that the process is conducted fairly and unbiasedly.

10. Concerning your question 12, successful claimants should be given a clear indication when they have passed their test or review along with an indication of the period during which they need not worry about further reviews so as to avoid unnecessary stress and worry for them and enable them to give their full attention to their daily task of managing of and coping with their disability.

There should always be an appeals procedure to address any injustices felt as the result of an unfavourable eligibility decision where the claimant could ask initially for a review and if required the option to lodge an appeal to a panel of independent members.

Claimants should be able to choose to have their assessment conducted at their home where a requirement to travel to an assessment centre will be an enormous stress, worry or impossibility for them. This is just as important for claimants who have a mental health component to their illness or disability.

Many disabled claimants will not be able by virtue or age or infirmity to process the necessarily lengthy and complex consultation document or be sufficiently eloquent or well enough to adequately detail and represent their feelings, difficulties, sufferings, wishes and views. I find this a totally exhausting task requiring

many days to put together and a burden on top of all that I have to do daily to maintain living needs. The consultation may favour the younger and computer literate claimants. Some form of readily accessible support, advice and advocacy is essential for vulnerable people receiving a test threat to their income to avoid wrong decisions being made in the drive to cut costs to avoid inequality.

11. Concerning your question 13, I used copies of my hospital medical discharge summary to report events during my frequent hospital inpatient periods. I did this methodically by sending photocopies to the DWP until one day I received a letter telling me not to do it anymore. Seems like we are damned if we do and damned if we don't.

12. Concerning your question 14, claimants need to know what the precise goal posts are to which to address their application rather than shooting in the dark.

13. Concerning your question 16, an item for item claim would be a bureaucratic nightmare which most claimants could not manage otherwise they would be working in an office were they fit to travel to one. Much fairer and easier to pay the set rate and leave the claimant the freedom to choose how to apply to money to service their needs.

14. Concerning your question 18, DLA mobility assessment and entitlement were helpful to me in being accepted for the life-changing Taxicard Scheme which meets vital transport medical, administrative and social needs which cannot be met by other services.

15. Concerning your question 20 any amalgamations of information should not combine universal benefits with means-tested ones to avoid covert slip into means-testing for benefits that are now universal. There is a particular danger concerning NHS free service and means-tested so called social care benefits which is a perverse distinction and needs to be at last addressed so that all care is free of charge and free of cheese paring analysis.

