

Disability Alliance Response R48

Response to the House of Commons Health Committee Inquiry into Co-payments and charges in the NHS

1. Introduction

1.1. Disability Alliance is a national registered charity with the principal aim of relieving the poverty and improving the living standards of disabled people. Our eventual aim is to break the link between poverty and disability.

1.2. We are a membership organisation with over 340 members which range from small self-help groups to major national disability charities. We are controlled by disabled people who form a majority of our Board of Trustees.

1.3. We provide information on social security benefits and tax credits to disabled people, their families, carers and professional advisers; undertake research into the needs of disabled people - with a particular emphasis on income needs, and promote a wider understanding of the views and circumstances of all people with disabilities.

1.4. We are best known as the authors of the Disability Rights Handbook, an annual publication with a print-run of 30,000, but also have a range of other user-friendly guides to benefits. We provide an information service and a popular website and have recently launched a Tribunal Support Unit to assist local disability and advice agencies with their advocacy work.

1.5. Our policy work is informed by our daily contact with disabled people and those who provide services for them. We undertake research into the needs of disabled people - with a particular emphasis on income needs. We have recently completed a major piece of work, together with the Centre for Research in Social Policy at Loughborough University, into the extra costs faced by disabled people – *Disabled people's cost of living – more than you would think*. Other recent work has covered disabled parents, families with disabled children and families with more than one disabled child. In 2003 we published *Withdrawing benefit from sick people* a short report highlighting the hardship caused by the rules under which disability benefits are stopped for people in

hospital. (Although the Government has since extended the period that benefits such as retirement pension can be paid while someone is in hospital, disability benefits still stop after four weeks).

1.6. We welcome the opportunity to submit evidence to this Inquiry.

2. Travel to hospital

2.1. There are a range of problems people have raised with us concerning the current arrangements. Under the current rules low income households can only get help with fares if they are attending hospital for treatment, or in the case of a child, accompanying the child for treatment. Many families tell us of the financial hardship they encounter because there is no help available for hospital visiting.

2.2. Families with disabled children who took part in our survey, published as *Helter Skelter*¹, told of their experiences with hospital visits and medical appointments.

2.3. One of the mothers reported on the problems she had with hospital appointments when her twins were babies *“It really was such a struggle. I had to get cabs everywhere. People forget that I didn’t just have a Down’s syndrome boy I had another baby as well ... my whole life was geared around..... double feeds – and umpteen hospital appointments, and I had no choice, I had to take M, and A was in hospital with bronchial pneumonia, asthma....”*

2.4. Another mother outlines the costs involved in taking her disabled daughter to Moorfields. *“ we go by train... if two of us go I the rush hour plus V it works out at £17 per adult, and if you get an early appointment you can’t get a cheap day return ... we usually go to McDonalds or something after the appointment, which is another tenner, so it’s about £50 just to go to Moorfields...”*

2.5. A further family whose disabled son was in hospital reported *“he’s allergic to hospital bedding so we’ve had to take bedding in for him.we take everything home... we’ve got duvet covers and sheets coming home everyday and we’re doing the washing at home”*. This family had lost their child’s disability benefit because

¹ **Helter Skelter, by Gabrielle Preston 2005, Centre for Analysis of Social Exclusion and Disability Alliance**

of the length of time he'd been in hospital and the father had taken unpaid leave from work. Their financial situation was serious.

2.6. Problems with the costs associated with hospital visiting was also a key issue to emerge in our survey of families with more than one disabled child, published as *Hard Working Families* in 2005. Families who took part in the survey reported that “*everything costs more with hospital visits*”, particularly when the child stays in for a protracted period, and a parent stays with them. This is now accepted good practice and is encouraged by the health service. Transport backwards and forwards to see the children who are at home and parking fees can be considerable additional costs. There are other issues relating to extra costs which are beyond the scope of this Inquiry but which put pressure on families – food for the parent staying with the child, loss of disability benefits (and consequent loss of carers allowance), care for children left at home.

2.7. Families tell us that hospitals rely on a parent to help care for a child or disabled adult son/daughter. We heard from a mother of an adult daughter with severe learning disabilities who was in hospital for a lengthy period. The mother had to stay in with her daughter because she could not feed herself and needed constant care. The hospital had insufficient staff to provide this. Yet the daughter lost her disability living allowance after 4 weeks and the mother lost her carers allowance.

2.8. One family with two teenage daughters, both of whom are severely disabled, and a six year old son with ADHD and allergic reactions told us of their experiences. The son is in and out of hospital “*sometimes twice a month*” because of his allergic reactions. When the girls are admitted to hospital they tend to go in for three or four weeks, during which time their mother stays with them. As her husband is also disabled when any of the children are in hospital the family has to pay someone to help out at home and prepare evening meals. “*I have to pay somebody to get a child into a wheelchair, get them ready for school. Before they get my son ready they have to catch him first.... There have been instances when we haven't been able to provide both morning and evening support*” in these instances the mother has had to rush home from the hospital to help get the children up and ready for school and then return to the hospital. Although the

hospital is reliant on her to help care for her son, it “*provides nothing*”. She has to pay her own fares and provide her own food.

2.9. Another family, living in East London, whose disabled son was admitted to a hospital in Stanmore (outer North West London) told us of their difficulties. While her son was in hospital his mother stayed with him. She had no car so had to travel by public transport. She had to return home every two to three days to sort out clothing, food, school uniforms, washing and ironing for her severely disabled daughter and three younger children. Her husband had to balance constant visits to the hospital to bring food with his caring responsibilities at home. The family did apply to the Social Fund for extra help but were turned down.

2.10. There can also be extra costs for medical appointments even when these are for the parent. A, who has two severely disabled sons, told us of an occasion when she had to take the boys with her when she had to see the doctor. “*They were both a bit poorly and my car broke down so I had to go by cab. As soon as we got there the eldest one crapped himself. The other little one was in the buggy. He was violently sick. The doctor told me to go home. That was another £8.*”

3. Hospital car parking

3.1. This is an issue that has been raised with us by many disabled people and families with disabled children. It has also been a key issue for cancer patients and is explored in detail in the recent report from Macmillan Cancer Relief ‘*Free at the point of delivery*’. Macmillan’s report concentrates on the problems encountered by patients attending for treatment. We would fully endorse their findings which echo our own experiences. However, parents who are having to remain in hospital to care for or just be with their disabled child report major problems paying high car parking fees. Yet the car can be necessary to transport other siblings around, or to bring in food and clothing or take home bedding. Families particularly resent these costs because they feel they are providing care which the NHS is not. Where this is coupled with the loss of disability and carers benefits the financial hardship is keenly felt.

4. Access to information

4.1. One crucial problem is lack of information about the low income scheme under which it is possible for people to get help with fares

to attend hospital. People told us how they discovered about the scheme by talking to other patients or came across the information almost by accident. There seems to be little effort put into informing families of the help available to them.

4.2. Disability Alliance is a key source of information for disabled people, our Disability Rights Handbook and our website are popular because they bring together information from a variety of sources. For organisations like ourselves obtaining information from the Department of Health about prescription charges and the low income scheme is problematic. The DoH website does not give information about the position in Northern Ireland, Scotland or Wales and nor does it refer visitors to primary sources (statute, regulations, guidance etc). I attach a page from the website as an example of the issue – the capital limits shown do not apply in all countries of the UK.

5. Prescription charges

- 5.1. Some people are exempted from charges due to their condition (eg. diabetes, epilepsy) and the need for them to take ongoing medication. There are a range of other conditions that also need ongoing medication which are not included in the list of exemptions and the logic for this is not clear to people.
- 5.2. People on income support are automatically exempt from prescription charges; people in receipt of some other benefits (such as pension credit guarantee, working tax credit with a disability element) or who qualify through the low income scheme can get an exemption certificate. The calculation for the low income scheme is very complicated and seems out of proportion to the amounts of money involved. We come across many examples of people with incomes just above the limit who need several items and cannot afford to get them all. This particularly affects people on incapacity benefit.
- 5.3. It is not cost effective for the Health Service to invest time and resources in a GP consultation, and possibly also further tests, and then have the patient failing to take the prescribed medication because they cannot afford all the items.

6. Recommendations

- 6.1 Expand the hospital fares scheme to cover visiting as well as attending for treatment.
- 6.2 Review and set limits on car parking charges
- 6.3 Extend the period for which disability living allowance and attendance allowance can be paid while people are in hospital to

bring this into line with the rules for retirement pension, income support and incapacity benefit.

- 6.4 Ensure that hospitals are obliged to provide food and laundry facilities for parents/carers who are staying in to care for a patient.
- 6.5 Improve the provision of information to patients and visitors about benefits and help with fares.
- 6.6 Provide better central information about NHS charging schemes across the UK.
- 6.7 Extend the range of conditions that qualify people for exemption from prescription charges, following consultation with the relevant disability and patient organisations.
- 6.8 Simplify and expand the low income scheme.

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Related link

- [nhs charges: third report of session 2005-06: vol. 2 written evidence \(pdf format\)](#)

Note: for pdf files you will need to [download adobe acrobat reader](#). To convert the pdf to alternative formats or for more information on accessibility go to [access adobe](#).

Basics about help with NHS charges

Entitlement to help with health costs (NHS prescription and dental charges, optical and hospital travel costs) is based on the principle that those who can afford to contribute should do so, while those who are likely to have difficulty in paying should be protected.

Who can get help

People can get help on age or medical grounds or by being in receipt of one of the exempting benefits or tax credits (see leaflet HC11 for more information).

Low income?

People who have to pay NHS charges may be able to get help under the NHS Low Income Scheme. The amount of help is based on a comparison between a person's income and requirements at the time that a claim is made or a charge was paid.

Capital limits

No help is available if a person has capital in excess of the limit: £8,000 (£12,000 if you and / or your partner are aged 60 or more or £20,000 for people who live permanently in a residential care home or nursing home).

How do I make a low income claim?

You need to complete form HC1 - this form cannot be downloaded from the web. You must obtain a hard copy. Ring the DH Publications Orderline on 0800 555 777 to get an HC1 and pre-paid return envelope. Jobcentre Plus offices and NHS hospitals should also have HC1s available. Some GPs, dentists, opticians might also have them.

When you have filled in the HC1 you should send it to: Patient Services, Sandyford House, Newcastle upon Tyne, NE2 1DB - in the prepaid envelope provided.

Form HC1 should be used

• to claim help with paying health costs for:

- NHS prescriptions
- NHS dental treatment
- NHS wigs and fabric supports
- Sight tests, glasses and contact lenses
- Travel for NHS treatment under the care of a consultant

You might be able to get them free, or get help with paying for them

• to claim help for:

- you
- your partner
- your children

• at any time before you need treatment

You **don't** have to wait until you need help with paying health costs

DON'T USE THIS FORM:

• you cannot get help if you or your partner have more than:

- £8,000 in property, savings or any other money (don't count the place where you live)
- £12,000 in property, savings or any other money if you and/or your partner are 60 or over (don't count the place where you live)

Note - if you have a partner, their property, savings or any other money is counted with yours

- £20,000 in property, savings or any other money if you live permanently in a residential care home or nursing home

• **you are already entitled to full help with health costs if you or your partner are getting:**

- Income Support
- Pension Credit Guarantee Credit
- Income-based Jobseeker's Allowance

or if

- you are named on Tax Credit NHS Exemption Certificate

But, if you paid any health costs before you were getting any of these benefits or credits, read the back cover of the form when you get it to see if you can claim your money back.