

25% ME Group Adult Social Services Survey

This is a report of the findings from a survey of adult members of the 25% ME Group, asking about their social care needs and their experiences of attempting to access care from social services.

What comes over loud and clear from this survey is a pressing need for care services and the existence of various barriers to accessing appropriate provision to meet these needs. These barriers include:

- refusal of care on initial assessment
- reduction and cessation of care packages
- limits on the nature and level of service available
- levying of unaffordable charges for service
- lack of awareness on the part of social services regarding the nature and impact of severe ME
- practical difficulties for a sick person in arranging care under the Direct Payments scheme
- difficulty achieving suitable non-family care for someone who is very severely affected

MEETING CARE NEEDS: OVERVIEW

100 people with severe M.E. responded to the survey, ranging in age from young adults to elderly people.

SOCIAL SERVICES CARE PROVISION

35 people were receiving care from social services:

13 were broadly satisfied with the care provided;

21 expressed dissatisfaction with the level and/or quality of care received;

(1 gave no indication of satisfaction with the care received).

A further 34 respondents were presently receiving no care from social services, but required care and had applied to social services at some point. They had either been refused care on assessment, or had had their care package stopped on review, even though their care needs had not lessened.

It is notable that as many patients had been refused care from social services from the outset or had had their care package stopped as were currently receiving care from social services.

PRIVATELY FUNDED PROVISION

Reflecting current trends in local authority social services' practice, the distinction between social services provision and privately paid workers was not always clear cut:

- patients may be asked to pay some or all of the cost of care supplied by social services;
- patients may employ agency staff, using funding through the social services Direct Payments scheme;
- local authorities may use agency staff to supply social services.

This meant that it wasn't always possible to be sure what scenario applied when a patient reported that they were receiving private care.

Around one third of respondents (n=30) were receiving care from a privately paid worker. Mostly this was combined with care from social services and / or family; however a few people (n=6) were relying entirely on private arrangements to meet their care needs.

FAMILY / VOLUNTARY CARE

Seven out of ten respondents were receiving care assistance from family or, less often, a voluntary organisation. For just over a third (n=38) family were the sole care providers.

Family care scenarios ranged from parents caring for sick children who now grown into young adults, to elderly spouses or parents coping with their own deteriorating health as well as attempting to provide adequate care to a severely affected M.E. patient. (Lack of awareness of the possible availability of care services and carers' support services was notable among elderly people.) There were also instances of young people looking after sick relatives.

NO CARE

Seven respondents were receiving no assistance at all to help with personal care needs.

This group included five people with severe ME who had applied for care from social services and had either been refused care on initial assessment, or had had their care package stopped on review - even though their care needs had not lessened.

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There are separate reports from this survey on:

- Occupational Therapy Service
- Family Carers' Needs and Circumstances

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RESPONDENTS' PROFILE

100 people with severe M.E. participated in the survey, ranging in age from young adults to pensioners, and resident in locations throughout the UK. Most had been ill for many years.

WHERE WERE THEY LIVING?

North of England	18
Midlands & East	30
<u>South inc. London</u>	<u>30</u>
England	78
Scotland	11
Wales	9
Northern Ireland:	1
TOTAL	99

(there was one non-response to this question)

At the time of the survey all were living at home. However several respondents indicated that they had been in residential care or had had a prolonged hospital stay the past.

HOW LONG HAD THEY BEEN ILL WITH M.E.?

0-4 Years	1
5-9 Years	15
10-20 Years	54
20+ Years	29
TOTAL	99

(there was one non-response to this question)

Just over half of respondents (54) had been ill for between ten and twenty years. A sizeable minority (29) had been ill for over 20 years. The remaining 16 had had ME for less than 10 years, though only one of them had been ill for less than five years.

HOW SEVERELY WERE THEY AFFECTED?

Mainly Housebound	59
Mainly Bedbound	38
Neither: Mainly uses Wheelchair	1
TOTAL	98

(there were 2 non-responses to this question)

Around four in ten respondents were bedbound or mainly bedbound; the remainder were mainly housebound. Fifteen respondents reported that they sometimes used a wheelchair, however, most remained mainly housebound. Only one person indicated that they were able to use their wheelchair to the extent that they were not mainly housebound.

GENDER	AGE GROUP						
	18-30	31-45	46-55	56-64	65+	not stated	All
Male	0	4	2	1	0	0	7
Female	6	25	27	22	11	0	91
not stated	0	0	0	0	1	1	2
Total	6	29	29	23	12	1	100

The vast majority of respondents were of working age, and those who were of retirement age (12 people) had all been ill for more than ten years. So the survey illustrates the needs and experiences of a group of severely affected people most or all of whom had fallen ill in youth or middle age.

It is notable that most respondents were female. It is possible that men face less difficulty in having their social care needs met since they are more likely than women to have a female carer living with them, and women have traditionally taken on the caring role in families. This would tend to make women with severe M.E. more likely to have to seek care from outwith the home, and thereby possibly more inclined to participate in a survey on social care needs and social services. A related issue is how male family carers cope with a caring role and with traditional domestic work that may not have been their responsibility before their partner became ill.

GATEWAY TO CARE: THE COMMUNITY CARE ASSESSMENT

Local authority social services departments normally conduct a Community Care Assessment (CCA) as a basis for decision making on care needs, in order to determine the level and type of care required. These assessments can be reviewed from time to time, and this may result in changes to care provision.

ARRANGEMENT MADE FOR CARE ASSESSMENT?

Yes	69
No	31

67 respondents had requested a Community Care Assessment (CCA); the remaining two had received social service care without a CCA, possibly prior to the introduction of the CCA system.

WHO HAD ARRANGED FOR THE ASSESSMENT?

Self	34
Family Member	9
Friend	2
Advocacy service	3
MP/ 'Counsellor'	2
Health Care Professional	13

The majority of assessments had been arranged by the patient themselves. Some had had help from family, and a few had relied a friend, an advocacy service, or an elected representative acting on their behalf.

(6 did not reply: total responses = 63)

The Role of Health Care Staff in Access to Care Services

Where a health care professional had been involved in arranging for assessment, this was most commonly the general practitioner: GPs had been involved in initiating seven arrangements for care. Hospital specialists had been involved in four referrals. The involvement of multiple medical professionals in some cases *e.g.* 'GP & hospital specialist', 'GP, health visitor, and occupational therapist' may attest to particular difficulties in achieving an arrangement for assessment - there were some instances of disputes between hospital & social services regarding responsibility for paying for care for a person who is very severely affected by M.E.

However, it is notable that relatively few arrangements for Community Care Assessment had been made by health professionals involved in the patient's care. And it would appear that people with severe ME who have had a CCA are far less likely to have been referred by health professionals than the client population in general.

- According to figures presented in a recent Green Paper on care, over one-third of people having a CCA are referred for the assessment by health professionals [1]. The incidence of 13 such arrangements in our survey (17%) compares unfavourably.
- However, this finding is in keeping with feedback provided in a prior members' survey, which indicated that a sizeable minority of severely affected ME patients - around one third of respondents - had no contact with healthcare professionals whatsoever. This was largely due to the reluctance of general practitioners to make home visits. [2]
- Furthermore, several responses to the present survey illustrated how poor experiences of the health service had deflected sick people from seeking to access *any* statutory services, including services to meet basic care needs.

Issues relating to the health service emerging from survey feedback, including the position of GP as potential 'gatekeeper', are covered in an appendix at the end of this report.

LENGTH OF WAIT FOR ASSESSMENT

1 week	4
2-4 wks	24
longer than 4 weeks	30*

(67 had requested CCA, 9 responses unclear)

* Including one person not yet assessed

Given the limits that severe M.E. places on a person's capacity to care for themselves, the time taken for requested assessments to take place - and for any subsequent services to be provided - is of considerable concern. Just under half saw an assessment underway within a month of request for CCA but the rest had had to wait longer. A substantial minority (12 people) reported that they had waited for over 4 months to get contact from social services.

Feedback on Impact of Wait for Assessment/Care Service:

- *“Delay from social services meant that care was not available, my condition deteriorated drastically as we struggled to cope. I feel that things might well never have become so awful if we had been given appropriate help at the outset. The delay cost us, and social services, dearly.”* [Lincolnshire]

QUALITY OF COMMUNITY CARE ASSESSMENT

The two thirds of respondents [66] who had had a Community Care Assessment were asked a number of questions about this assessment:

- **Do you feel the Social Worker/Care Manager took on board all your care requirements in order to properly assess your daily care needs?**
Just over half of those who replied [56%] answered ‘no’.
- **Was the Community Care Assessment explained clearly to you?**
Almost half of the relevant respondents felt that the assessment process had *not* been clearly explained. Only 39% were confident that the assessment process *had* been clearly explained.
- **Were you allowed to be fully involved in the CCA?**
Just under half said that they had been allowed to be fully involved. Some of those who replied in the negative said that they had simply been too ill - others would have wished more involvement.
- **Did you feel that your particular disabilities/illness were recognised?**
Around two thirds felt that their particular disabilities / illness had not been recognised during the assessment process.
- **What level of understanding did you feel that the assessor had of:**
 - **M.E. in general?** Three-quarters felt that the assessor’s understanding of M.E. in general had been poor
 - **The effects of the illness on you?** Almost as many [70%] felt that understanding had been similarly lacking in respect of how the illness was impacting on them
 - **Your cognitive problems?** There was a particularly poor level of understanding among assessors regarding cognitive problems [80% ‘poor’]
 - **The variability and fluctuating nature of symptoms?** 75% felt that the assessor’s understanding of the characteristic variability and fluctuating nature of symptoms had been poor

Feedback on Community Care Assessment

- *“Rationed care for everyone in Perth. No understanding of the impact of ME on my needs and disbelief at what I said. Poor communication between departments & with me.”*
- *“Since my daughter has gone into adult services not been treated that well. No information on meeting held. No letters what happen at these meetings. We sent assessment papers back with alteration made to them but never heard any more. That was over a month ago. Can’t ring social worker as gives my daughter nightmares when she sees her and lady shouts when she goes in my daughter’s room.”* [Comments provided by the carer of a young adult living in the East Midlands].
- Person *“did 6 months in nursing home last year”* and was referred for OT and CCA by staff *“at neuro unit where I spent 3 months”*. She rates the assessor’s understanding on all points listed as ‘poor’ on the basis that *“she just copied old report”* and presently has no dedicated social worker or care manager because *“they’re re-organising.”* She is dissatisfied with the quality of social services care received. [North Yorkshire]

BALANCE OF ATTENTION IN THE ASSESSMENT PROCESS

Which of these areas did you feel needed to be met the most? (Physical, Emotional, Social Domestic)

- respondents overwhelmingly replied that assistance with *physical care needs* was most important
- next highest priority was accorded to *domestic needs*
- assistance to meet *social needs* and *emotional needs* took a much lower profile

It is interesting to compare this feedback with reports of the emphasis placed by social services on these respective areas of need when conducting Community Care Assessments:

Did you feel that the correct amount of attention was given to these areas of need ?

Area of Need	Yes	No	Don’t Know	Total
PHYSICAL (eg. Personal Care/ Mobility)	31	29	4	64
EMOTIONAL (eg. Counselling)	8	48	8	64
SOCIAL (eg. Getting out, contact with people)	15	43	6	64

DOMESTIC (eg. Essential Household Chores)	23	38	3	64
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NOTES RE ABOVE TABLE: (1) Two of the 66 people who had been through CCA did not reply, so n=64; (2) The need for assistance to get out of the house to conduct necessary business may have been variably be viewed as physical (since this includes 'mobility') or social (since this includes 'getting out'); (3) 'Social needs' apparently reflected carers' needs for a break to socialise in some cases.

- **Physical Needs** Respondents were fairly evenly divided as to whether or not appropriate attention had been focussed on the high priority area of *physical care needs*, with approximately half saying 'yes', and half 'no'.
- **Domestic Needs** Respondents were less likely to feel that the correct amount of attention had been given to *domestic needs* (38%), which followed physical in respondents' priority rankings.
- **Social Needs** Approximately a quarter (26%) felt that the correct amount of attention had been paid to *social needs*. This was a relatively low priority area for respondents, so it is more likely that they felt that too much emphasis had been placed on this rather than too little.
- **Emotional Needs** The lowest incidence of satisfaction was with the degree of priority that had been accorded to *emotional needs* (14%). Notably, this was also a low priority area for respondents, so it would appear that social services tend to over emphasise emotional needs when conducting Community Care Assessments for people with severe M.E.

Feedback on Balance of Attention in Assessment Process

- *"Focussed too much on Social Needs not understanding that I was unable to go out and how little strength I had to talk or socialise (too weak)."*

COPING WITH COMMUNITY CARE ASSESSMENT

- Several respondents had been too ill to be involved in the assessment any way, and had been represented in the course of their assessment by family or an advocate.
- Around half of those who had been involved in their assessment had had someone with them while being assessed. In about half of these cases, that person had felt that they were listened to by the assessor.
- Only a few of those who had been assessed felt that they had been well enough to cope *during* the assessment [12/66 patients; 18%].
- Responses indicate that *all* of those who had participated in the assessment had been exhausted *afterwards*.
- Very few got over the adverse impact of participating in the assessment in a day or two. The vast majority had taken 3 days or longer to recover from the adverse impact of the assessment process, with around a quarter taking over a month.

OUTCOME OF COMMUNITY CARE ASSESSMENT

WAS A CARE PACKAGE GRANTED? Around three quarters of those who had been assessed for care by social services had received some form of care package following the assessment. This clearly applied to 52 of the 69 who had approached social services seeking care (75%).

However, the level of service provided may have fallen short of what was required – for example: *"Some aspects of care required not started following assessment, due to lack of funds."* [South East England]

In a further six cases it was unclear whether care had been refused on initial assessment or had been granted but subsequently stopped on review. Ten respondents reported that they had been refused care on assessment. One person was awaiting assessment at time of survey.

REFUSAL, REDUCTION OR LOSS OF CARE SERVICE

Around a quarter of those who had requested a Community Care Assessment had been refused service. A further concern is the high proportion of those initially granted care who subsequently had their care package reduced or stopped altogether on review, *even though their condition had not improved*. This applied to around half of those who had initially been granted care. These people were commonly advised at the review stage that they did not fit social services criteria, sometimes with reference to changes in eligibility criteria because of funding constraints. People could also be viewed by social services as ‘not requiring service’ at the review stage.

REFUSAL OF CARE ON ASSESSMENT

Ten respondents reported that they had been refused care on assessment. In a further six cases it was unclear whether care had been refused on initial assessment or had been granted but subsequently stopped on review.

Feedback on Refusal of Care

- *“Cambridgeshire social services ‘do not support people with ME’. This was a direct quote made to my health visitor after my assessment by them. My Occupational Therapist was present at my assessment and even stated that I would be hospitalised without help. I did not appeal due to lack of energy and stress it would involve (took 6 months between ‘agencies’ to get that far. Adult and child services were passing me as I have a 5 year old son.)”*
- Matters took a serious turn for the worse for one elderly woman when she moved out of London, where she had been granted care services, to the southwest. A CCA was arranged by *“consultant physician at Royal London Homoeopathic Hospital who requested – via new GP - increase in care (for 8-12 hours). ... refused. ... Direct Payments taken away even though I was more ill. NOTHING put in place. Even though consultant suggested that I continue with them. Main reasons - I was not incontinent and did not need a hoist to get out of bed.”* Presently she receives care only from a privately paid *“cleaner twice a week when I can get one.”* She reports *“Have not recovered [from the assessment] because help & support refused.”*
- *“I have never had any care services, despite being seriously ill for 13 years. I was assessed over the phone in 1997. Requested CC package – told me there was no funds & had already been assessed.”* This person lives in Yorkshire and is paying for private care provision.

REDUCTION OR LOSS OF CARE SERVICE ON REVIEW

Community Care Assessments can be reviewed from time to time, and this may result in changes to care provision.

Has your care package ever been reduced or stopped at a Community Care Assessment Review, although your condition remained the same or had deteriorated?

Yes	21	The ‘yes’ group comprised 12 people whose care had been stopped completely, and 8 whose care package had been reduced; one response was unclear whether care had been reduced or stopped altogether.
No	24	

In addition, one person had been refused care on reassessment in a new area. There were also several instances where care had been reduced or stopped at the patient’s request; however, aspects of social services attitude and/or care delivery commonly had a bearing on this decision (some examples are included in the feedback below).

Were you told that you could Appeal Against the Decision?

Yes	7	Most had <i>not</i> been informed that they were entitled to appeal against a decision to reduce or stop care provision.
No	14	

Some of those who were aware of their right to appeal or complain lacked the capacity to do so. For example, one woman had had all care stopped *without* a Care Assessment Review and *without* any prior notification that carers’ would cease to attend - and *“still no explanation”*. She was living alone and had no family to call on for care assistance, but did not make a formal complaint because she was *“unable – too ill”*.

Feedback about Reduction or Loss of Service

Respondents were asked if funding constraints or assessment as no longer meeting social services criteria had played a part in their care package being reduced or stopped altogether. Here are some instances where this had been cited:

LACK OF FUNDS

- Mother and carer, aged 82, reports that her daughter “needs full time monitoring”. Care services had been withdrawn, citing lack of funds. They are now paying privately. As an elderly carer she is not eligible for Carers’ Allowance. She observes: “There is a real lack of understanding of the needs and limitations of severely affected ME sufferers on the part of social services in Langridge District Council.” [Sussex]
- “I have 6 hrs a week & did have 9 but 3 hours were taken away 2¹/₂ years ago due to lack of funds.” [Wales]
- Person apparently had one visit from a social worker at which she was informed that she wouldn’t get care due to lack of funds. She is presently receiving no care. [Sussex]

‘DO NOT FIT SOCIAL WORK CRITERIA’

- Woman is mainly bedbound and has been severely affected by M.E. for over 20 years. She had her package stopped on the basis of lack of funds and not fitting social services criteria, and is now entirely reliant on family for to meet her care needs. She reports: “I receive no service. Before my service was withdrawn and then refused the quality was very poor!” [South West England]
- Woman is mainly bedbound and receives high level care component of Disability Living Allowance. Care from social services had been stopped on review, on the basis ‘do not fit social work criteria’. She is presently receiving care from family/friends only. [West Midlands]
- Another woman, also mainly bedbound and in receipt of DLA Care component at high rate, had had her care package reduced on review, on the basis ‘do not fit social work criteria’ and ‘lack of funds’. [Yorkshire]
- “Told ‘the goal posts have changed’ ” - care package reduced. [Hampshire]

Authorities arguing over responsibility for care could also be an issue in this context:

- One person explained that she was deemed not to fit social work criteria “as actually TOO severe & Primary Care Trust + social services arguing over whose remit and funding!”. She had spent 8 months in a care home, then 2 years in a general hospital: the Primary Care Trust had arranged for Community Care Assessment prior to her discharge from hospital. [South East of England]

Other reasons why care packages had been reduced or stopped on review included:

REFUSAL TO PROVIDE CARE IF FAMILY CARER ‘AVAILABLE’

- “Was only given help because my husband and carer broke his leg – care package ended when he could walk without 2 crutches. Would never have got any help otherwise!” [Northern Ireland]
- “I did ask for help from social services but was assessed as only needing help with housework and shopping - my husband was helping me with other things. I think as my husband was my carer they didn’t consider I needed other care help although he was working full time. They stopped providing this type of help about 10-12 years ago so I now get housework etc. done privately.” [Greater Manchester]
- Care was stopped because my youngest child had just turned 4 (school age) therefore I no longer need help! Plus lack of funds. The M.E. did not stop simply because our son reached school age. We asked again several times, but were refused as there were ‘no children involved’. So who did they think would do the school runs, shopping, washing, cleaning? – a 4 year old should walk home alone and prepare his own meals because his mother was ill in bed! We paid for private child minder, and still pay for private domestic help. The carer has to hold down a full time job.” This woman has had no care service for the last 17 years. [West Midlands]

OTHER CIRCUMSTANCES/REASONS

- Care stopped on review, after she “made complaint about home help and social worker” [Tayside, Scotland]
- Care stopped following Assessment Review : “said I was psychiatric, not physically ill.” [Cambridgeshire]
- Social services say work could be done in less time. [Lothian, Scotland]

CARE CUT AT PATIENT’S REQUEST

Commonly aspects of the care service provided had had a bearing on this decision. For example:

- “Attempted to cut it right down so that it was not workable or you had nothing.” [Midlands]
- “Package no longer delivered what I needed or my spouse so it was stopped.” [South East]
- “Had to have bath/shower 10.30 a.m. Mondays. Too early for me and not always well enough.” Had asked for care to be reduced/stopped because of the unsuitable scheduling of the service. [Pembrokeshire, Wales]

Others referred to affordability as a barrier to care, for example:

- “I was too ill. Couldn’t afford it.” This person is mainly bedbound and now pays privately for care. [Surrey]

- “Recently cancelled, can’t afford” [Ayrshire, Scotland]

FUNDING ISSUES: SUMMARY OVERVIEW

Many respondents reported that they had had their social services care package reduced, or withdrawn altogether, or had found that some aspects of the care required were not provided on assessment, due to lack of funds. There were also instances of patients being refused care on the basis of lack of funds *without* a Community Care Assessment having been conducted. This could happen in the course of a single visit from a social worker, or even over the telephone.

Charges levied for care by local authority social services departments were not always affordable, obliging some people to cancel the service.

Such restrictions commonly resulted in severely affected ME patients and their families paying for private domestic and care services from their own funds.

In these circumstances it is particularly important that the patient receives any benefits to which they may be entitled, including the correct level of Disability Living Allowance care component, to assist with funding the care required. However, respondents to the survey included bedbound patients paying privately for care following refusal of care from social services, who had been assessed to receive only low level DLA care component.

DISABILITY BENEFITS

Most respondents were receiving Disability Living Allowance. However only 1 in 3 had been awarded DLA Care Component at the high rate, commensurate with the care needs that would be expected for a person who is severely affected by M.E.

RECEIVING DISABILITY LIVING ALLOWANCE?

Yes 89
No 11

We don’t know whether the 11 people who were *not* receiving DLA had applied for this benefit and been rejected, or whether they had not applied.

Those who were in receipt of DLA were asked at which level care component of DLA had been awarded. One response was unclear, and one was consistent with receiving mobility component only. The remaining replies were:

LEVEL OF CARE COMPONENT AWARDED

Low 25
Medium 32
High 30

There was no clear relationship between the level of severity reported by respondents and the level at which DLA care component had been awarded. For example, seven people who were mainly bedbound were among those who had been awarded the lowest rate of DLA care component.

Only 1 in 3 had been awarded Care Component at the high rate.

Feedback/Example:

- “Severe Disablement Allowance changed to DLA without assessment. Given Mobility component for life.” However, despite previously having been on Severe Disablement Allowance, this person had been awarded low level Care Component of DLA.

Difficulties in accessing DLA faced by people with M.E. are well documented from other sources - you can find out more about this in an appendix to this report.

ONGONG LINKS WITH SOCIAL SERVICES

Respondents were asked if they had a dedicated social worker or case manager to call on, and how often they saw a social worker or care manager.

DO YOU HAVE A DEDICATED SOCIAL WORKER/CARE MANAGER?

Yes 18
No 13

A total of 31 people who were currently receiving care from social services replied to the question. Just over half did have a dedicated social worker or care manager, however a substantial minority did not.

HOW OFTEN HAVE YOU SEEN A SOCIAL WORKER / CARE MANAGER IN THE LAST 5 YEARS?

Levels of ongoing contact were low - around half of those who were currently receiving care from social services [47%] had seen a social worker or care manager three times or less in the previous five years. Not surprisingly, those who had a dedicated social worker or care manager to call on were more likely to report frequent contact.

Among those with more frequent contact - *i.e.* four or more times over the previous five years - were eight people who had had their care package stopped or reduced on review, suggesting that frequency of contact can reflect moves to reduce or stop care, rather than a straightforward attentiveness to the client and their care needs.

QUALITY OF CARE

Respondents were asked about the quality of care received from their care providers. This could be care provided by social services staff or agency staff in the employ of social services, or care arranged via a Direct Payment from social services, or from private staff funded by the client.

ARE YOU SATISFIED WITH THE QUALITY OF CARE THAT YOU RECEIVE FROM SOCIAL SERVICES?

Yes 12
No 19

(35 were receiving; 4 non response: n=31)

Approximately a third of those who were currently receiving care from social services [37%] indicated that they were satisfied with the quality of care received. The majority – around six out of ten – were dissatisfied with quality of care from social services.

ARE YOU SATISFIED WITH THE QUALITY OF CARE THAT YOU RECEIVE FROM PRIVATELY PAID STAFF?

Yes 19
No 7
'Quality Varies' 1

(around 30 were receiving; 27 replied)

Comparative figures indicate that there was a much higher incidence of satisfaction with the quality of care provided by privately paid staff – though some of the 'no' responses here were illustrated with emphatic comments, indicating that the quality of such care does indeed vary.

ARE YOU SATISFIED WITH THE QUALITY OF CARE THAT YOU RECEIVE THROUGH DIRECT PAYMENTS?

Yes 11
No 1
'Has Reservations' 1

Satisfaction with quality of care was highest amongst those who were making arrangements for their care via a Direct Payment from social services. (More on care arranged through Direct Payments below.)

Feedback regarding Quality of Care

Some respondents raised serious questions about the quality of care provided. For example:

"They were very rough when I was so weak and painful. ... They gave me verbal violence!"

Comments regarding poor quality of care commonly related to social services' use of agency staff:

"Quality of care from care agency – disgusting. Different carers all the time. Never correct times. People being carers who are not hospitable/ lazy/ unhygienic/ cannot comprehend our situation. Agency changes care plan set by social services to whatever they think so I'm (as a carer) constantly complaining to social worker who sorts but it then goes back to how it was." [Essex]

"Quality and reliability of private care companies accepting vouchers extremely variable." [Lancashire]

"Care agency staff are lowly paid and most of them lack initiative. I am always having to check up on the work they are doing. They are making life harder work." [Lancashire]

MAKING A COMPLAINT

A surprisingly high proportion of those who had had dealings with social services care had made a formal complaint at some time. Several others had wished to make a complaint, but had been prevented because they were too ill to do so.

HAVE YOU EVER NEEDED TO MAKE A FORMAL COMPLAINT ABOUT ANY ASPECT OF SOCIAL WORK INVOLVEMENT?

Yes	27	Over a third of those who had had dealings with social services had made a formal complaint at some time [27 people; 38%].
Yes, but too ill	4	
No	46	
(not stated / unclear)	6)	

Several others who had had a grievance had lacked the capacity to get involved in the social services complaints procedure, illustrating the practical difficulties for a sick person in complaining about poor quality or lack of care.

Feedback on Barriers to Lodging a Complaint:

- Respondent had wished to make complaint but had been *“too ill and weak to go through with it”*. She reports: *“Total lack of understanding of ME. All they are after is the money. Care agency staff are lowly paid and most of them lack initiative... They are making life harder work. The other day they had put wet laundry that wasn’t dry into drawers and it started to smell damp so I had to re-do it all again myself.”* [Lancashire]
- *“Needed (to make formal complaint) but no energy and no support”*. This elderly lady had been refused care when she relocated to a different local authority and health service area. [South West England]

TO WHAT EXTENT WAS YOUR COMPLAINT UPHELD?

Fully	12	Most complaints had been upheld, fully or in part.
Partially	7	
Not At All	5	
Ongoing	2	

(one non response: n=26)

Feedback regarding Complaints:

- *“When I requested appropriate levels of funding I was told I must have a complete reassessment by a multidisciplinary team of 7 consultants including a psychiatrist and a psychologist. This large number would cause a MAJOR relapse and does not take account of my condition. My original diagnosis of ME was questioned & Soc. Services & Health Authority wanted a complete reassessment after 22 years of illness. I made a formal complaint which was upheld.”* [Tyne & Wear]
- *“At the very beginning the social worker didn’t say we were entitled to a financial assessment as my husband only on a low wage. It’s been sorted now. Went to the very top to complain + we didn’t pay.”* [North Wales]

GETTING IT RIGHT

Amidst the many difficulties reported, it is important also to acknowledge that some respondents had had appropriately positive experiences of social services. For example:

“The assessor took on board and believed what I told him about my illness and disability.” [Yorkshire]

“Excellent, understanding care manager & OT.” [Devon]

ARRANGING FOR CARE THROUGH DIRECT PAYMENTS

Recent years have seen the introduction and expansion of the Self Directed Care (Direct Payments) route to care provision, where the person requiring care is awarded a sum of money which they use to make their own arrangements for care services to meet their needs.

IF YOU RECEIVED A CARE PACKAGE, WERE YOU ALSO TOLD ABOUT THE DIRECT PAYMENTS SCHEME?

Yes	36	
No	9	Most of those who had received a care package had been informed about the Direct Payments option.
'already knew'	1	
(11 non responses)		

WERE YOU FULLY INFORMED ABOUT THE ADVANTAGES/DISADVANTAGES OF THE DIRECT PAYMENTS SCHEME?

Yes	16	However, just over half of those who had been told about this option felt that they hadn't been fully informed about the advantages and disadvantages of the Direct Payments scheme.
No	19	
(2 didn't reply here: n=35)		

DO YOU RECEIVE DIRECT PAYMENTS?

Fourteen respondents were receiving Direct Payments, representing around four in ten of those who were receiving care from social services at this time. All but one stated that they were employing their own carers, or personal assistant (the remaining person did not respond to this question).

DO YOU RECEIVE SUPPORT TO MANAGE YOUR CARERS EFFICIENTLY?

All but two had received some form of support to manage the scheme. Among this group (n=11), this had taken the form of: payroll assistance (10), help with recruitment (9), and/or help with paperwork, such as contracts (7). However, it was by no means clear that people were receiving all the help needed in this regard. For example, one very severely affected patient, who was entirely dependent on for her care on arrangements made via Direct Payments, and who preferred to take this route to care, commented on how difficult managing this was for her:

"Began to receive Direct Payments end of 2007 after years of trying + planning. All support partial only but very inadequate. Paperwork a HUGE problem still."

Several others, who were *not* currently receiving Direct Payments referred to the inherent difficulties of administering this system for a very sick person as presenting significant barriers to this route to care:

"I didn't receive any help, not even when I contacted social services with a query/problem. They knew less than I did! Was satisfied with the finance itself, when I had it, but not any support."

"No Support to administer when I previously had them."

"Someone visited us to explain what was involved with Direct Payments. ... too complicated for someone with ME"

"I really need Direct Payments, but I would need some support hours allocated to help me manage this and none are allowed."

"Though I can get Direct Payments I'm not well enough to do all the business side of employing my own carers."

Also, since care is means tested, the outcome could be ironic for people wishing Direct Payments. One family noted:

"We wanted access to Direct Payments [but found out that this] would end up costing us out of our own pocket."

DIRECT PAYMENTS - OVERVIEW

Findings from this survey support the view that the self-directed option can be a rewarding way of meeting care needs, affording an element of choice and control. For example, it is notable that the incidence of satisfaction with quality of care was highest among those who were arranging for care support via Direct Payments:

- **84% of those who were self managing social care via direct payments were satisfied with the quality of care service received ; this compares to**
- **70% of those who were receiving care from privately paid staff, including care agencies; and**

- 39% of those who had care directly provided by local authority social services.

At the same time, however, it was clear that people with severe M.E. face considerable barriers to achieving effective self-direction of arrangements to meet their care needs. This applied particularly to severely affected people who were coping as best they could without a family carer, and who required support to make the necessary arrangements to translate a direct payment into practical care but had no family to assist with this either. *The ironic result is that people with high care needs and without a family member to help meet these needs are, at the same time, most reliant on social care services and least well placed to organise care through Direct Payments.*

These factors underlie the very real concern expressed by some respondents regarding where the present direction of social care policy and practice might lead them. For example:

I am very worried about the fact that social services Home Care Support Workers are going to cease to exist as social services are planning to give all future care work to the private agencies. Social services will be only running a 6 week care package for clients who can be rehabilitated. They are called re-enablement workers. I've had private care before and it was dreadful and though I can get Direct Payments I'm not well enough to do all the business side of employing my own carers. I am very frightened about my future.

FEEDBACK ON BARRIERS TO ACCESSING APPROPRIATE CARE PROVISION

This section draws together feedback on some of the major barriers experienced in accessing suitable care provision.

LIMITS ON THE LEVEL AND NATURE OF CARE SERVICES PROVIDED

A number of respondents highlighted issues regarding the restricted nature of the service that social services provide to physically disabled adults, including some who had been receiving care services in the past, which had ceased after social services withdrew from the area of provision required. For example:

"Our social services only provide personal care (bathing, dressing). You must pay privately for everything else. Social services won't even provide meals. ... Social services provide very little in the way of care." [This person had been refused social services following a Community Care Assessment.]

"Package no longer delivered what I needed or my spouse so it was stopped."

"My daughter was sent a form to fill out – 'a care assessment' eventually a social worker called on the phone. We never saw her. She said she could offer 'personal care' but not going shopping or cleaning house which is what we needed."

"They're not allowed to lift a lightweight wheelchair in the boot/car so I can't go out when I'm up to it – not very often. Due to Health & Safety blanket ban on wheelchairs."

"There is a huge difference in support from social services for learning difficulties adults and physically disabled adults. Only one scheme caters for physically disabled adults and it's very limited by funding shortage/ staff shortage."

"Had to have bath/shower 10.30 a.m. Mondays. Too early for me and not always well enough." [Person had asked for this element of the care package to be stopped because of the unsuitable scheduling of the service.]

FINANCIAL BARRIERS

Not only were some people requiring to pay for care privately due to restrictions on the social services care provided, several pointed out that *social services* were levying charges for care at a level that they were unable to afford (see feedback on funding constraints, presented above).

Other illustrations of financial barriers to care included:

"I get no [financial] help whatsoever as my pension in £2.60 over the limit to get help assessed at 3 hours minimum @ £17 per hour. I get help now privately and sometimes I have a lodger and pay them for help. I never see a social worker as, I am told, I am 'intelligent enough' to help myself!" Asked if able to live at home without assistance, this patient replied: "No, but I have to".

"My wife receives a care package of 63 hours a week + I care for her during evenings + get up at night to care for her as required until day carer arrives. This costs £174 per week contribution from the Independent Living Fund (ILF) + Social Services financial package. There is no funding to increase my wife's care package." (This couple are required to pay towards the cost of care from social services, topping up

the funding provided by the local authority - so the same care staff are paid by a combination of social services funding and the client's own money.)

"Because we have too much savings it is cheaper to employ private people anyway."

"would like one (privately paid worker), however money is an issue for me." [This person had been awaiting Community Care Assessment for around two years at time of survey.]

LACK OF AWARENESS ABOUT THE NEEDS OF A PERSON WITH SEVERE ME

This emerged in a number of contexts. For example:

"Can't ring social worker (to try to find out present 'state of play'; in the light of lack of communication) as gives my daughter nightmares when she sees her and lady shouts when she goes in my daughter's room."

"Cambridgeshire social services 'do not support people with ME'. This was a direct quote made to my health visitor after my assessment by them. My ME OT was present at my assessment and even stated that I would be hospitalised without help."

"Total lack of understanding of ME."

[On move from another area] *"... had to manage on our own and just continue to do so because we cannot face any more aggravation from social services. Luckily, things have improved sufficiently for us to be able to cope well enough. Also actually life is easier without all the problems that carers can cause."*

DIFFICULTY PROVIDING APPROPRIATE EXTERNAL CARE TO PEOPLE WHO ARE VERY SEVERELY AFFECTED

Very severe M.E. brings with it both a high level of need for care and strictures regarding what can be tolerated (noise etc.) which make achieving appropriate care provision intrinsically more difficult.

For example, the husband and carer of one woman, who was receiving some care from social services, described their situation as follows:

"Am satisfied with the quality of services received in our circumstances + no extra funding available. Don't receive all the help needed (as a carer) due to lack of funds and also wife's condition – she can't tolerate noise. Had carers giving 24 hour care for 2 weeks a year – but difficult due to number of bedrooms in house + agencies never cover 24/7 completely so I can't go away"

We have spent more than £10,000 on mobility equipment and adaptations for my wife. My wife receives a care package of 63 hours a week + I care for her during evenings + get up at night to care for her as required until day carer arrives. This costs £174 per week contribution to the Independent Living Fund + Social Services financial package. There is no funding to increase my wife's care package.

It enables me to have some independence – seeing friends, attending own medical appointments. I am 75 years old. My own health problems are receiving ongoing help – memory problems can cause severe difficulties but using more 'notes' to help this."

Where a person was very severely affected, the person and their family might feel that only someone who knew the person and their needs well would be able to care for them. For example:

"Totally bedbound. This patient is too ill to receive any outside services. Patient is too ill to be supported by anyone else" The young woman's carers (her parents) completed the questionnaire.

"Requested cut in hours as I couldn't cope with someone in my home for long. My mum knew my condition and I preferred having her tend my needs."

Another difficulty where a person was very severely affected was that social services and health services might dispute responsibility for care provision, ironically resulting in a person with very high care needs receiving restricted care. For example, one woman who describes her condition as *"Very severe ME 100% 'bedlocked' "* and *"not able to do hardly anything & no movement"* explained that she was deemed not to fit social work criteria *"as actually TOO severe & Primary Care Trust + social services arguing over whose remit and funding!"*. She had previously spent 8 months in a care home, then 2 years in a general hospital, and the Primary Care Trust had arranged for Community Care Assessment while in hospital.

She had clearly had quite a difficult time, with *"Many different social services experiences during the course of my ME."* For example:

Re proper assessment of care needs taking on board all care requirements: *"No; have 'fought' for many years for this".*

Were you allowed to be fully involved in the Community Care Assessment?: *"Only recently as 'pushed' for this".*

Unfortunately she had lost the support of her partner due to lack of carers' support:

"My former partner 2000-2005 – no help offered or given ever despite years of support to me. Hence 'former' partner."

Things were beginning to look up, however: *"Only last few months has 'improved' with new care managers!"*

APPENDICES

THE HEALTH SERVICE - FEEDBACK

Health Service Staff as Barrier to Accessing Social Care

- *“Medical personnel I have come in contact with have no conception of how ill this disease makes me feel. Medics + care have a disturbing apathy towards it – I can do without this attitude. We’ll go it alone as a family for as long as possible.”* (Further specific details of poor medical care were provided.) Very unsatisfactory experiences at the hands of health professionals had discouraged this person, who lived in Lanarkshire, Scotland, from seeking help from social services to meet her care needs.
- *“On moving to Lincolnshire, the GPs refused to even consider any help, we were in temporary accommodation for a few months, had to manage on our own and just continue to do so because we cannot face any more aggravation from social services. Luckily, things have improved sufficiently for us to be able to cope well enough.”*
- *“Our GP is not interested in my ME so I never see her as she doesn’t [do] house calls. Her lack of involvement means I receive no medical attention and I feel I’m blocked from accessing NHS or social services. We cope the best we can by ourselves which isn’t ideal but at least I’m in control and can choose what is best for me.”* [West Midlands]
- *“We have had no help or advice from GP. Do not know what help we should get but need help. My father is 78 and struggles caring for wife and daughter.”* This feedback came from a middle aged woman in Somerset, who had never had a Community Care Assessment and wasn’t receiving Disability Living Allowance. She had requested referral for Occupational Therapy Assessment, which was refused. Re Community Care Assessment, she reports *“didn’t know this was available”*. It would appear that her GP is her sole point of contact with statutory services, and has been unwilling to refer her for support or to provide information about help available.

Other Feedback re Health Service

- *“Appealed for out of area referral but was refused although there is NO M.E. specialist consultant in this area.”* [Somerset]
- *“Local M.E. group worked hand in hand with NHS to set up a psychiatric clinic for M.E. which has influenced social services.”* [Yorkshire]
- *“Still believe M.E. sufferers are disbelieved, more so those that are in 25% Group with members of NHS quoting ‘other ME/CFS get better’. I don’t believe we have moved on, in that people still treat us like malingerers, and think they are justified in their behaviour.”* [Tayside, Scotland]

ACCESS TO DISABILITY LIVING ALLOWANCE: A Decade of Documented Difficulty

National Audit Office and Select Committee on Public Accounts Reports

In November 2003, the Comptroller and Auditor General at the National Audit Office produced a report titled *“Getting it right, putting it right: Improving decision making and appeals in social security benefits”* [3]. This report presented and discussed statistics on decision making and appeals in the benefits system. The poorest performance having previously been found to occur in benefits requiring the examination of medical evidence, such as Disability Living Allowance, the National Audit Office found no conclusive evidence that the accuracy of decision-making had since improved. This report was subsequently considered by the Select Committee On Public Accounts [4], which observed:

“Getting benefit decisions right is vital to the credibility of the social security system. Incorrect decisions can cause uncertainty and hardship... Administrative efficiency is also reduced as cases are reconsidered or go to an appeal.”

Considering the NAO’s findings, the committee concluded that that *“Too few decisions are right first time”*.

Against the background of this generally unsatisfactory situation, it is notable that statistics on access to Disability Living Allowance relating to claimants with M.E. suggest even more cause for concern.

Research by the Centre for Longitudinal Studies

Research on Disability Living Allowance (DLA) was conducted by the Centre for Longitudinal Studies (CLS) in 2002. [5] Firstly, the CLS conducted a review of prior research evaluating the administration and impact of DLA, and concluded:

“Certainly the research summarized above indicates that take up rates of DLA are low and that the administration of DLA is inadequate. To address this issue effectively requires an understanding of who eligible non-recipients are and how the current system is failing them.”

The CLS then looked specifically at awards of DLA to people with ‘CFS/ME’ and feedback about experiences of claiming DLA, as an example of a disabling condition that is poorly understood. Notably, they considered that:

- *“although in legislation eligibility for DLA does not depend on the claimant’s disabling condition, in practice the assessment process is grounded both structurally and informally in a stereotypical notion of disability, i.e., conditions manifesting visible, static and relatively permanent signs or symptoms, of a level of severity that does not vary unpredictably across individuals;*
- *individuals with poorly understood disabling conditions experience difficulties in accessing health and other services and face a lack of sympathy and stigmatization, which can affect claiming behaviour; and*
- *poor understanding of these conditions and the stigma they carry can affect the behaviour of decision makers and others who contribute to the adjudication process.”*

The statistical analysis conducted revealed that:

“First awards were made to people whose principal disabling condition was CFS/ME less often at the initial stage and more often at appeal than would be expected on the basis of figures relating to all disabling conditions.”

The study then presented two elements aimed at illuminating the ‘hows’ and ‘whys’ behind the statistical data.

Firstly, statistics on decision making were scrutinised to identify other conditions in respect of which DLA was awarded less often at the initial stage and more often at appeal, in comparison to aggregate figures for all disabling conditions. It became evident that these conditions shared:

“Features that could make administration of DLA problematic. For example:

- *Effects that are difficult to decide in the terms defined by the DLA regulations because of e.g. fluctuations in severity, and symptoms that are invisible and/or do not readily translate into functional incapacities;*
- *Effects that vary from one patient to another so that the effects on individual claimants are difficult to assess;*
- *Poor understanding and lack of sympathy for the condition.”*

The results of this analysis are interpreted as providing:

“Clear evidence of an interaction between the level of difficulty associated with the administration of DLA and the claimant’s main, disabling condition.”

Secondly, in depth interviews were conducted with people with ‘CFS/ME’ - claimants and eligible non-claimants – and with benefits advisers, including ME specialist advisers. These approaches were supplemented by qualitative material from a national survey conducted by a patient organisation (ME Support). The aim was to address questions relating to potential barriers to the provision of cogent evidence that a person fulfils DLA eligibility criteria. They further conclude:

“The qualitative findings constitute consistent and overwhelming evidence that the experience of having CFS/ME is associated with the claimant facing particular difficulties in the submission of accurate, comprehensive and relevant evidence to support claims.”

(These qualitative findings are covered in more detail below.)

The paper concludes:

The research has opened up an issue with wide implications because it presents evidence that having certain disabling conditions may prejudice access to disability benefits. This flouts the principle of ‘equality of treatment’.

Research by M.E. Charities

It is interesting to compare the above analysis with the findings of research carried out by M.E. charities, including the 25% ME Group. It emerges that, in comparison to the average for all DLA claims, claims for DLA by people with ME are both very much more likely to go to appeal [2, 6]; and considerably more likely to succeed at the appeal stage [2].

- During the mid-1990's, 4% of all first awards of Disability Living Allowance were granted on appeal [5]. This means that, of those claimants who were ultimately deemed to be eligible, 1 in 25 had had to take their case to appeal.
- During the same period, among claimants with 'CFS/ME', the proportion of first awards granted on appeal was 13% [5]. This means that, among this particular group of claimants, 1 in 8 of those who were ultimately deemed to be eligible had had to take their case to appeal.
- Recipients with severe ME, canvassed in 2004, were even more likely to have had to take their case to appeal with half of awards arising from first claims having been granted only on appeal [2]. This means that 1 of every 2 claimants who were ultimately deemed to be eligible had had to take their case to appeal.

Summary

- **Following a review of statistics on decision making and appeals in social security benefits, the Select Committee of Public Accounts observed that the poorest performance was found to occur in *"benefits requiring the examination of medical evidence, such as Disability Living Allowance"* and concluded that *"Too few decisions are right first time."***
- **Against this background, it is notable that statistics relating specifically to claimants with ME indicate an even less satisfactory situation. In comparison to the average for all DLA claims, as criticised by the Select Committee for Public Accounts, such claims are both very much more likely to go to appeal, and considerably more likely to succeed at appeal.**

What the Future Holds?

These difficulties are likely to become even more entrenched with the proposed introduction of 'objective medical assessment' as a barrier to access to Disability Living Allowance. This has been proposed on the basis that it will save money - the explicit intention is to make fewer awards of Disability Living Allowance.

Announced in the June 2010 emergency budget as part of the government's plans to reduce the deficit in public accounts, this proposal gives rise to considerable concern. Although M.E. has a devastating impact on a person's quality of life and capacity to function, and research studies have demonstrated a range of biomedical abnormalities - with over 3,000 published papers to date - there is no basic diagnostic test. And the reality for the overwhelming majority of M.E. patients is that they do not have access to the sort of specialist tests that are required to establish objective evidence of dysfunction. Often the only evidence about impact comes from the patients themselves, and such accounts hold little weight with assessors.

This is already a considerable barrier to accessing Disability Living Allowance – as evidenced in the paper published by the Centre for Longitudinal Studies and feedback provided by 25% ME Group members, which we believe is in line with feedback provided to other national M.E. charities. In our view, the proposed change will further entrench this difficulty.

QUALITATIVE RESEARCH - DETAILS

***"Access to benefits is triggered by evidence that the claimant fulfils eligibility criteria. This raises questions about ways in which having CFS/ME as one's principal disabling condition might affect claimants' and potential claimants' abilities to provide cogent evidence."* [5]**

With this in mind, the research conducted by the Centre for Longitudinal Studies set out to answer specific qualitative questions:

- *Do symptoms such as fatigue, poor concentration and increased vulnerability to stress constitute barriers to claiming and obstacles to pursuing claims successfully?*
- *Do the invisible symptoms and fluctuating nature which characterise CFS/ME make it particularly difficult to demonstrate care and mobility needs?*
- *Do the lack of understanding about CFS/ME and the stigma attached to it affect claiming behaviour in ways that are prejudicial to successful claims?*
- *Do the lack of understanding about CFS/ME and the stigma attached to it prejudice the accuracy of evidence presented by Examining Medical Practitioners?*

A range of evidence supporting an affirmative answer to each of these questions emerged:

“The qualitative findings constitute consistent and overwhelming evidence that the experience of having CFS/ME is associated with the claimant facing particular difficulties in the submission of accurate, comprehensive and relevant evidence to support claims.”

Some of the specific points illustrated in this evidence are extracted below.

FROM: *"A Poorly Understood Condition: Disability Living Allowance and People with CFS/ME"*; Cathie Hammond; Social Policy and Administration Vol.36, No.3, June 2002, pp254-274.

Do symptoms such as fatigue, poor concentration and increased vulnerability to stress constitute barriers to claiming and obstacles to pursuing claims successfully?

The evidence very clearly and consistently gives a positive answer to this question. For example:

- ♦ Beliefs that the process would worsen one's condition, that DLA is rarely awarded to claimants with CFS/ME before appeal, and claimants' experiences of fighting other battles were additional barriers to claiming.
- ♦ During medicals, many claimants felt *"too ill"* to describe their needs accurately, and reported feeling *"so ill"* by the end that they would have *"signed anything"*.
- ♦ Many appellants are too ill to attend tribunals, one collapsed before entering the room, and others are too exhausted to answer questions.

Do the invisible symptoms and fluctuating nature which characterize CFS/ME make it particularly difficult to demonstrate care and mobility needs?

- ♦ Awareness of the difficulties involved in translating experience into the questions on the claim forms constituted a barrier to claiming.
- ♦ Claimants find it difficult to answer questions on the forms because they *"aren't suitable for the illness"*. It is particularly difficult to describe:
 - the cumulative and after-effects of activities, especially in relation to the main meal test (which asks whether the claimant can prepare a meal) and estimates of the distance the claimant can walk without severe discomfort.
 - cognitive symptoms such as poor attention and memory, hypersensitivity to light and sound, because *"the form is aimed at classically diagnosable mental health problems, and mine don't fit"*.
 - help needed when going out because the questions are *"asking you what you would do if you didn't have ME ... because the fatigue actually stops you doing things ... You can't enjoy them"*.
 - fluctuating effects. The form asks claimants to specify how many days a week they have difficulties, and this is problematic because *"it's not the same every week"*, and difficulties are not *"on or off"*.
- ♦ The physical examination is not useful for assessing the needs of people with CFS/ME because there is *"nothing to show"* and examination can only provide a snapshot of the effects of the illness. Consequently, physical examinations feel *"unnecessary"*, *"irrelevant"* and *"intrusive"*.
- ♦ Manifest symptoms are not always reported to the Examining Medical Practitioner. One can only speculate about whether this results from incompetence or is a consequence of the symptoms defying medical terminology.
- ♦ All the advisers mentioned that many of the medical reports they see fail to translate the effects of CFS/ME into needs relevant to the purposes of DLA.

Do the lack of understanding about CFS/ME and the stigma attached to it affect claiming behaviour in ways that are prejudicial to successful claims?

- ♦ Pressure to understate needs is an obstacle to successful claims.
- ♦ Anxiety that the illness and therefore one's right to the benefit would be *"questioned"* by doctors, acquaintances and/ or friends was a barrier to claiming and pursuing claims.
- ♦ The expectation of being turned down unfairly was a common barrier to claiming, and the possibility of losing benefit already awarded was a barrier to pursuing claims. Claimants and advisers related these fears to the controversy surrounding CFS/ME.

Do the lack of understanding about CFS/ME and the stigma attached to it prejudice the accuracy of supporting evidence?

The submission of additional evidence may be particularly pertinent to claims made by people with CFS/ME because of the difficulties associated with demonstrating needs and the possibility that the Adjudication Officer does not understand the illness.

- ♦ On the basis of the 20,000 cases she deals with each year and discussions with other disability groups, a policy officer suggests that *"there is a reliance on medical evidence to back up the claim that the claimant is physically unable to perform a task"* and that the Benefits Agency use Examining Medical Practitioners (EMPs) and General Practitioners (GPs) to collect this evidence. She adds *"For conditions like ME ... medical knowledge would be best from someone who is much more knowledgeable about the claimant's condition."*
- ♦ Indeed, claimants and advisers alike describe *"inaccurate"* and *"trivializing"* reports by GPs and EMPs resulting from disbelief in the condition and poor understanding of its effects (in the opinion of claimants and advisers), and the lack of contact between the claimant and the GP arising from problems getting to the surgery and the absence of available treatments.
- ♦ However, reports from specialists are difficult to obtain because many claimants are not under a specialist, or if they are, rarely see them. Consequently, claimants sometimes submit evidence from alternative practitioners, but the indication is that these carry little weight with Adjudication Officers.

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