

# Factors associated with work status in chronic fatigue syndrome

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<b>Background</b>	Work status in people with chronic fatigue syndrome (CFS) has not been extensively researched.
<b>Aims</b>	To explore occupational outcomes in patients with CFS by socio-demographic, well-being and disease characteristics.
<b>Methods</b>	We assessed cross-sectional data from patients attending a UK specialist CFS treatment service between 1 January 2007 and 31 December 2014. The main outcome was self-reported current employment status: currently in employment, temporarily interrupted employment or permanently interrupted employment. Other variables included sex, age, ethnicity, education, marital status, CFS duration, fatigue severity, anxiety, depression, activity limitations and functional impairment. We used multinomial logistic regression models to identify factors associated with current work status.
<b>Results</b>	Two hundred and seventy-nine (55%) patients were currently working, with 83 (16%) reporting temporarily interrupted employment and 146 (29%) stopping work altogether. Factors strongly associated with permanently interrupted employment were older age (adjusted odds ratio (AOR) 5.24; 95% CI 2.67–10.28), poorer functioning (AOR 6.41; 95% CI 3.65–11.24) and depressive symptoms (AOR 2.89; 95% CI 1.82–4.58) compared to patients currently working. Higher educated patients (AOR 0.60; 95% CI 0.37–0.97) and being in a relationship (AOR 0.34; 95% CI 0.21–0.54) were associated with being currently employed. Anxiety symptoms were common; 230 patients (45%) met caseness criteria.
<b>Conclusions</b>	Many patients with CFS were not working. This was exacerbated by high levels of depressive symptoms. Health professionals should assess co-morbid mental health conditions and consider treatment options when patients with CFS present themselves. The early involvement of occupational health practitioners is recommended to maximize the chances of maintaining employment.
<b>Key words</b>	Chronic fatigue syndrome; employment; mental disorders; occupation; well-being.

## Introduction

International estimates suggest that 35–69% of people with chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), are not working due to their illness [1]. With an estimated prevalence of CFS between 0.2 and 0.56% among adults in the UK [2] and the chronic nature of the illness, the high level of work incapacity contributes substantially to its huge economic cost. Indeed, the economic cost due to the discontinuation of employment in patients with CFS before they access specialist services in the UK is estimated at £100 million annually [3]. Even when patients are able to stay in employment, their performance is often impaired as they experience challenges in conducting work-related

duties. Hence, many patients report being forced to cut down their hours or change jobs [1,4].

To further our understanding of the impact of CFS, it is essential to explore occupational outcomes, as they are a critical measure of prognosis and the cost of illness. This cross-sectional study examined work status among CFS patients and whether there were any differences in occupational outcomes by socio-demographic, well-being and illness characteristics.

## Methods

Patients attending an out-patient chronic fatigue research and treatment unit in London were included in the current study after written consent was obtained ( $n = 746$ ).

## Key learning points

### What is already known about this subject:

- Estimates suggest that 35–69% of people with chronic fatigue syndrome, also known as myalgic encephalomyelitis, are not working due to their illness.
- Despite this, occupational outcomes in UK patients with chronic fatigue syndrome have received limited attention.

### What this study adds:

- Our results suggested that 45% of patients reported temporary or permanently interrupted employment.
- Co-morbid depression and anxiety were common as well as high levels of functional impairment.

### What impact this may have on practice or policy:

- Health professionals should assess co-morbid mental health conditions and consider treatment options when patients with chronic fatigue syndrome present.
- Greater and more effective liaison is recommended between occupational health and chronic fatigue syndrome clinics to maximize the chances of maintaining appropriate employment. Efforts should be directed to examining the effectiveness of supported employment schemes among patients with chronic fatigue syndrome.

A CFS diagnosis was confirmed by a clinician using the Oxford criteria [5]. Patients were excluded if:

- CFS diagnosis was not clinically confirmed;
- the initial assessment was only partially completed;
- they self-reported other health conditions that could have impacted on their employment status such as cancer, eating disorder, epilepsy and bipolar disorder;
- they were retired or were looking after their home; and
- they did not answer the question about their employment status.

All data were routinely collected when patients visited the unit for their initial assessment. The baseline data used in this project were collected from 1 January 2007 to 31 December 2014. The main dependent outcome variable was current employment status. Patients' responses to a question about their current work status were combined in three categories: (i) employed, including patients who reported full- and part-time work, casual work or being a student; (ii) temporarily interrupted employment (TIE), including patients reporting temporary sick leave; and (iii) permanently interrupted employment (PIE), including permanently sick or disabled patients and those unemployed.

Other measures used were the 11-item Chalder Fatigue Questionnaire (CFQ) to measure fatigue severity [6,7], the 10-item Short-Form (SF-36) Health Survey to measure difficulties in physical functioning [8] and the 5-item Work and Social Adjustment Scale (WSAS) to examine functional impairment [9]. A higher score indicates worse fatigue severity on the CFQ and greater functional impairment for the WSAS, whereas a lower score on the SF-36 indicates poorer physical functioning. A score >20 on the WSAS was used as a threshold to indicate moderately severe functional impairment. The SF-36 and WSAS have been

shown to be valid and reliable for use in patients with CFS [7,10]. The Hospital Anxiety and Depression Scale (HADS) was used to assess symptoms of anxiety and depression [11]. Each subscale consists of seven items, and scores >10 were used as a threshold to indicate anxiety or depression. We also measured patients' perceptions on the nature of their symptoms and whether their current or past job was physically or mentally demanding.

The data were analysed using STATA v. 15.0. Descriptive statistics were used to describe the sample by employment status. Univariable multinomial logistic regression was used to investigate the association between employment status (dependent variable) and socio-demographic characteristics, well-being, job and disease characteristics (independent variables). Subsequent multivariable models were adjusted for age, sex and education. A pro-rating procedure was applied to impute missing data for the measures used. Missing data points were imputed with the mean score of the individual patient [12]. This was only done if the amount of missing data for one particular measure was ≤25%. This is a common and appropriate method to use when dealing with missing data and is unlikely to lead to any significant bias [12].

The Audit Committee of the Psychological Medicine Clinical Academic Group of King's Health Partners approved the study. Therefore, no ethical approval was needed as data collection is routine and analyses were conducted as part of service evaluation.

## Results

After excluding those not meeting the inclusion criteria ( $n = 238$ ), we included 508/746 (68%) patients in the study. Two hundred and seventy-nine (55%) of CFS

patients reported being employed; 83 (16%) were temporarily and 146 (29%) were permanently unable to work due to their illness. Patients who reported being unemployed ( $n = 53$ ) were included in the PIE group as among those who disclosed the duration of their work interruption, the majority had been unemployed for over 3 years. In contrast, this was only about 8 months for those who reported being on sick leave. Patients in employment were significantly more likely to be in a relationship than those currently not employed (Table 1).

Older patients and those with a longer disease duration were significantly more likely to have interrupted their employment permanently (Table 1). Twelve (2%) patients suggested that their symptoms were predominantly psychological, whereas the majority, 302 (63%), reported that their symptoms were both physical and psychological. One hundred and forty patients (61%) who had interrupted their employment, whether temporarily or permanently, reported depression or anxiety symptoms.

**Table 1.** Baseline characteristics of patients affected by CFS by current employment status ( $n = 508$ )

	Currently employed ( $n = 279$ ; 55%)	TIE ( $n = 83$ ; 16%)	PIE ( $n = 146$ ; 29%)	<i>P</i> value
Gender, <i>n</i> (%)				
Male	82 (29)	16 (19)	41 (28)	
Female	197 (71)	67 (81)	105 (72)	NS
Age (years)				
Mean (SD)	35.8 (11)	37.36 (10)	41.6 (10)	–
Ethnicity, <i>n</i> (%)				
White British	241 (88)	65 (79)	121 (84)	
Other	34 (12)	17 (21)	24 (17)	NS
Marital status, <i>n</i> (%)				
Single	135 (49)	46 (55)	99 (69)	
In a relationship	139 (51)	37 (45)	44 (31)	<0.001
Education, <i>n</i> (%)				
None/secondary school	54 (20)	24 (29)	43 (30)	
Polytechnic/University	221 (80)	59 (71)	103 (71)	< 0.05
CFS duration, <i>n</i> (%)				
≤2 years	93 (37)	33 (45)	30 (23)	
≤4 years	55 (22)	10 (14)	22 (17)	
≤8 years	50 (20)	12 (16)	30 (23)	
>8 years	52 (21)	19 (26)	49 (37)	<0.01
Nature of symptoms <sup>a</sup> , <i>n</i> (%)	$n = 271$	$n = 81$	$n = 135$	
(Mainly) physical	88 (33)	27 (33)	40 (30)	
Physical and psychological	172 (64)	54 (67)	94 (70)	
(Mainly) psychological	11 (4)	0 (0)	1 (01)	NS
Work is very physically demanding, <i>n</i> (%)	$n = 269$	$n = 80$	$n = 133$	
No, not at all/a little bit	196 (73)	40 (50)	69 (52)	
Yes, quite a lot/very much	72 (27)	40 (50)	64 (48)	<0.001
Work requires a lot of concentration and mental strain, <i>n</i> (%)	$n = 273$	$n = 80$	$n = 134$	
No, not at all/a little bit	41 (15)	6 (8)	17 (13)	
Yes, quite a lot/very much	232 (85)	74 (93)	117 (87)	NS
Fatigue severity (CFQ) (range 0–33)	$n = 278$	$n = 82$	$n = 143$	
Median (IQR)	22 (21–29)	29 (25–32)	29 (22–32)	<0.001
WSAS (range 0–40)	$n = 277$	$n = 83$	$n = 145$	
Median (IQR)	21 (14–27)	31 (24–34)	31 (26–34)	<0.001
Physical functioning (SF-36) (range 0–100)	$n = 275$	$n = 81$	$n = 144$	
Median (IQR)	60 (40–75)	35 (25–50)	30 (13–55)	<0.001
Anxiety (HADS), <i>n</i> (%)	$n = 272$	$n = 81$	$n = 144$	
Case (>10)	120 (44)	32 (40)	78 (54)	NS
Depression (HADS), <i>n</i> (%)	$n = 272$	$n = 81$	$n = 145$	
Case (>10)	52 (19)	33 (41)	64 (44)	<0.001

NS, non-significant.

<sup>a</sup>Nature of symptoms as reported by the patients.

The median duration of sickness absence in those temporarily out of work was 8.4 months compared to 6 years among those who interrupted their work permanently. About one in four patients who were temporarily out of work received statutory sick pay and over one in three received incapacity benefits. Of those currently in employment, the average hours worked per week ranged from 2 to 60 h with a mean of 29.9 h (SD 12.6).

Multivariable analyses suggested that currently not working was most strongly associated with perceived

functional impairment (WSAS; adjusted odds ratio (AOR) 6.72, 95% CI 3.31–13.65 TIE and AOR 6.41, 95% CI 3.65–11.24 PIE), older age, with the strongest association found among those over 50 (AOR 5.24, 95% CI 2.67–10.28 PIE), and depressive symptoms (AOR 2.87, 95% CI 1.66–4.98 TIE and AOR 2.89, 95% CI 1.82–4.58 PIE) (Table 2). Further, those who experienced CFS for more than 8 years were significantly more likely to be permanently unable to work (AOR 2.33, 95% CI 1.29–4.21). Patients in a

**Table 2.** Factors associated with current employment status among patients affected by CFS (reference group those who are currently working;  $n = 279$ )

Variable	Univariable		Multivariable <sup>a</sup>	
	TIE ( $n = 83$ )	PIE ( $n = 146$ )	TIE ( $n = 83$ )	PIE ( $n = 146$ )
Gender				
Male	1	1	1	1
Female	1.74 (0.95–3.19)	1.07 (0.68–1.66)	1.84 (1.00–3.41)	1.29 (0.81–2.05)
Age				
<30 years	1	1	1	1
30–39 years	2.71 (1.37–5.34)	2.34 (1.28–4.30)	3.19 (1.59–6.41)	2.57 (1.39–4.78)
40–49 years	2.38 (1.17–4.82)	3.07 (1.69–5.59)	2.60 (1.27–5.33)	3.16 (1.72–5.82)
50+	1.65 (0.66–4.10)	4.96 (2.57–9.59)	1.88 (0.74–4.76)	5.24 (2.67–10.28)
Ethnicity				
White British	1	1	1	1
Other	1.85 (0.97–3.53)	1.41 (0.80–2.48)	1.85 (0.96–3.56)	1.40 (0.78–2.53)
Education				
None/secondary school	1	1	1	1
Polytechnic/University	0.60 (0.34–1.05)	0.59 (0.37–0.93)	0.60 (0.34–1.05)	0.60 (0.37–0.97)
Marital status				
Single	1	1	1	1
In a relationship	0.78 (0.48–1.28)	0.43 (0.28–0.66)	0.76 (0.45–1.27)	0.34 (0.21–0.54)
CFS duration				
≤2 years	1	1	1	1
≤4 years	0.51 (0.23–1.12)	1.24 (0.65–2.36)	0.50 (0.23–1.11)	1.15 (0.59–2.23)
≤8 years	0.68 (0.32–1.42)	1.86 (1.01–3.43)	0.65 (0.31–1.39)	1.91 (1.02–3.59)
> 8 years	1.03 (0.53–1.99)	2.92 (1.66–5.15)	1.00 (0.51–1.97)	2.33 (1.29–4.21)
Work is very physically demanding				
No, not at all/a little bit	1	1	1	1
Yes, quite a lot/very much	2.68 (1.61–4.49)	2.49 (1.61–3.84)	2.72 (1.61–4.57)	2.55 (1.62–4.03)
Work requires a lot of concentration and mental strain				
No, not at all/a little bit	1	1	1	1
Yes, quite a lot/very much	2.18 (0.89–5.34)	1.22 (0.66–2.23)	2.28 (0.92–5.68)	1.14 (0.60–2.20)
Fatigue severity (CFQ)	1.12 (1.07–1.18)	1.07 (1.03–1.10)	1.12 (1.06–1.18)	1.06 (1.03–1.10)
Physical functioning (SF-36)	0.97 (0.96–0.98)	0.96 (0.95–0.97)	0.97 (0.96–0.98)	0.96 (0.95–0.97)
WSAS				
Case (>20)	6.84 (3.39–13.80)	6.61 (3.83–11.42)	6.72 (3.31–13.65)	6.41 (3.65–11.24)
Anxiety (HADS)				
Case (>10)	0.83 (0.50–1.37)	1.50 (1.00–2.25)	0.82 (0.49–1.36)	1.50 (0.98–2.29)
Depression (HADS)				
Case (>10)	2.91 (1.70–4.97)	3.34 (2.14–5.22)	2.87 (1.66–4.98)	2.89 (1.82–4.58)

<sup>a</sup>Adjusted for sex, age (continuous) and education.



relationship (AOR 0.34, 95% CI 0.21–0.54) and those with a higher level of education (AOR 0.60, 95% CI 0.37–0.97) were more likely to be employed. Job demands, fatigue severity and poorer physical functioning were associated with currently not being employed.

## Discussion

In this study, 45% of patients with CFS were unable to work, temporarily or permanently, due to their illness. This concurs with Collins *et al.* (2011) who found that half of the patients with CFS seen in specialist clinics in the UK discontinued their employment due to their illness [3]. Among patients in the UK who presented to primary care, one in three had suspended their work or reduced their hours in the past 3 months due to their CFS symptoms [13]. One possible explanation for the higher rates in secondary care is that patients with more severe CFS symptoms and higher levels of functional impairment are more likely to access specialist CFS services.

Our study had some limitations. We only included patients who presented to one CFS out-patient treatment unit in South-East London, so caution must be exercised in generalizing the results to patients accessing other services. Another limitation is that sparse information was available about the specifics of an individual's employment status. For example, patients who stated they were unemployed were included in the PIE group as their average duration of unemployment was more comparable to patients in this group than those reporting to have interrupted their work temporarily. Further, we did not have any information on whether those who retired qualified for ill-health retirement. As with all exploratory studies of this kind that examine factors associated with an outcome of interest, future research is needed to confirm the results, thereby ruling out any findings being the result of chance. A strength of the current study was the use of valid and reliable measures to assess health and well-being.

We found high levels of psychiatric co-morbidity, with over 40% of patients currently not employed reporting depressive symptoms compared to 20% of those employed. Irrespective of employment status, over 45% of patients reported symptoms of anxiety. This finding is of interest, as a systematic review by Cairns and Hotopf (2005) suggests that psychiatric morbidity is associated with poorer prognosis in patients with CFS [14]. Even without additional psychiatric morbidity, rates of recovery are low, with approximately 1 in 20 patients with a clinical diagnosis of CFS having fully recovered over the duration of follow-up and about 4 out of 10 reporting improvement [14]. Indeed, a longitudinal study following up younger people with CFS indicated that depression was associated with a higher chance

of receiving permanent disability benefits at follow-up [15].

Therefore, it is essential that health professionals assess for co-morbid mental health conditions and consider treatment options. However, health professionals should be considerate in how to discuss a potential psychological component of the condition with the patient. If it is clear that stress has played a part in contributing to the patient's difficulties, they are encouraged to have a discussion about it. The health professional may introduce (i) the potential relationship between stress and fatigue; (ii) the symptoms, which include fatigue, associated with different systems in the body (gastric, musculoskeletal, cardiac, autonomic nervous system) that stress can generate; and (iii) how the stress system involving the hypothalamic-pituitary-adrenal axis regulates stress. Acknowledging that some of the patient's symptoms are physical in nature will help the patient to engage in discussion about how to move forward. If the patient is depressed with a risk of self-harm then that should be prioritized clinically in the usual way.

Given the evidence suggesting that good work is beneficial for health [16], it is important to ensure that we encourage and support people with CFS to remain in employment, or when their symptoms improve, re-enter the work force. Comparable rates of occupational impairment have been found among people with long-term disabilities, with less than half of them being employed [17]. Research has emerged that supported employment schemes, such as individual placement and support programmes, contact with the workplace and multi-component return-to-work interventions, are effective for those with mental disorders [18,19]. At the moment, it is unclear whether this type of employment-related intervention is beneficial for patients with CFS. Our findings indicate that people who reported their last job as very physically demanding were more likely to be out of work; this was not the case for those in a job that relied more heavily on cognitive ability. This suggests that exploring ways in which a patient's current occupational role can be adjusted may be helpful. Providing help to support patients find suitable employment elsewhere should be considered. It is possible that it is more difficult to adjust physically demanding jobs to ensure patients can remain employed, especially if patients consider their CFS symptoms to be mainly physical. Alternatively, only 12 patients in our sample reported that their CFS symptoms were predominantly psychological in nature, so the study may have been underpowered to thoroughly explore the association between job type and type of CFS symptoms. To ensure that people can stay in employment for the longest period possible, it is essential that support and treatment are available at the early stages of the illness when work impairment is limited.

The early involvement of occupational health (OH) practitioners is recommended to maximize the chances of maintaining appropriate employment. We recommend greater and/or more effective liaison between OH and CFS clinics. In practice, people with CFS symptoms often need longer than employers typically accommodate for during a phased return to work (e.g. 4 weeks is usually not long enough). However, recommendations such as 1 h a week working from home for the first month increasing to 2 h a week in the second month, etc. are unlikely to be considered reasonable or feasible by employers. Liaison between CFS clinics and OH could help to facilitate effective recommendations for work rehabilitation that employers might be persuaded to accommodate, which might help people with CFS symptoms return to work and retain their employment.

In conclusion, a substantial number of patients accessing specialist CFS services were currently not employed and this was highest among those reporting greater functional impairment and depressive symptoms. Health professionals should take into consideration the potentially high levels of psychiatric co-morbidity when treating CFS patients. Further research efforts should be directed into exploring the effectiveness of interventions to help CFS patients maintain their job or re-enter the work force when symptoms subside.

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## Competing interests

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