

25 % Severe M.E. Group & CARERSTOGETHER.CO.UK

Carer's Pack - updated Jan 2004

Who are we ?

There are about 5.7 million carers in Britain (3.3 million women and 2.4 million men). It is also estimated that there are between 18000 and 40000 young carers.

- 42% of carers are men; 58% of carers are women
- 54% of carers are aged between 35 and 59, with 19% aged under 35.
- 56% of carers are the chief income earner for the household, and 50% of carers are in employment.
- 67% of people cared for are over 64

It has been calculated that carers save the government more than £59 bn a year by their unpaid efforts.

Despite the 1999 "National Strategy for Carers" - the Government's carers package, many of the UK's six million carers continue to feel isolated and unrecognised in their role. It is not easy living on benefits .Carers Allowance , for example, is the lowest of all income replacement benefits, being only 60 per cent of the value of other long-term benefits.

Carers & Severe ME.

The Chief Medical Officer's Working Group Report (2002) describes the impact of ME upon carers :

"CFS/ME has a profound effect on every part of life. Many carers reported that their world felt it had been 'turned upside down' and they had feelings of 'despair'.

It is conservatively estimated that ME costs the country more than 4 billion pounds a year in lost earnings and benefit payments. Yet from 1997-2001 there was no Government funding whatsoever into the underlying physical causes of the condition. Last year though over £8 million was allocated for the development of NHS services in England.

The ME sufferer faces , in the words of MP Tony Wright, a double burden : "They must cope with an illness that to a great extent destroys their lives and suffer the prejudice and ignorance that has followed the illness around."

The suffering hour to hour, is relentless. One study, for example, has suggested that patients with this condition had more dysfunction than those with multiple sclerosis, and that in ME/CFS the degree of impairment is more extreme than in end-stage renal disease and heart disease.

Hopefully, following publication of the Chief Medical Officer's Report, the situation will begin to improve; as the report states : "inaction due to ignorance or denial of the condition is not excusable.

ME is a profound challenge on very level. It can be very hard indeed to care for someone who does not "get better", whose illness goes on for days, weeks, months, years, decades.

One of the hardest lessons to learn is how to live with the illness, rather than constantly seeking for a cure; for this can impose an intolerable pressure on both parties. To live with the illness is to enter into the day-to-day , unpredictable reality of ME, not so much as a "carer" but as a partner. It takes everything to do this and one needs to think very carefully about one's own needs and support.

Quality of Life - Who is Caring for the Carers ? Betty Dowsett

Introduction

Any change in the equilibrium of family life will have profound effects on all its members. In every household where there are sufferers from ME, siblings, parents and grandparents will all experience frustration in varying degrees. Unfortunately this illness is almost unique in attracting disbelief and derision among family members as well as from the public at large (1). Thus, it is not only the patient but the carer as well who will suffer the pain and

exhaustion of the illness and have their own special needs (2).

What do we know about the problems of carers ?

Very little ! - and this is for two main reasons :

a). Because the carer is usually in a close personal relationship with the patient (eg. the mother or spouse may be afraid to speak out for fear of disloyalty to the patient and of causing further distress by rocking the boat!)

b). Because, in the case of children, teenagers and young people, those in charge are almost inevitably the mother (apart from a very few grandparents, friends and marriage partners). Anyone providing care for those in this age group, are likely to face horrendous problems with medical and educational professionals and possibly with social workers and other welfare officials. Even in the 2nd millennium many carers of young people with ME may still be bullied and under threat of having children removed into care.

Research into the Problems of Carers

1. Why has so little been done ?

a). Carers' problems have only recently encroached upon Government financial policies - that is to say there is an immense monetary gain for the Health & Social services if patients can be kept out of hospital by the voluntary efforts of unpaid carers (3).

b). Demo-graphic changes, such as population ageing and alterations to medical practice, including shorter inpatient

stay and earlier discharge home, have increased the burden of carers. At the same time, the majority of carers are in older age groups, have little political influence and because of emotional strain and exhaustion, have little energy to protest.

2. Research Methods

a). Hitherto these have been based on patient questionnaires and confined to "flag-ship" problems eg. Alzheimer's disease and similar geriatric disabilities such as prostate enlargement and cancer.

b). There is now a need for separate questionnaires specially addressed to the carer and (realising that patients often have overlapping illnesses) making them non-disease specific.

3. Some Research Findings

a). In general the quality of life for carers is worse than that of patients. In particular, those whose souses bear a larger proportion of the work than any other and have enormous unmet social, medical and psychological needs, to say nothing of prolonged lack of rest, leisure, sleep, loss of appetite and poor nutrition.

b). The patients' mental condition has more impact upon the carers' distress than their medical condition.

c). Illnesses which confine the minder to the house, which involve social isolation, feeding and washing the patient, financial burdens arising from loss of career and employment, modifications to house and way of life are the most destructive of the carer's health and psyche.

d). Nursing activities are undoubtedly related to a high level of morbidity and mortality and, in the case of a caring spouse, leads to a feeling of being in limbo, neither married nor widowed.

e). Other family members and children will be more or less severely affected by the carer's exclusive concentration upon the patient, causing them to lose self esteem and feel jealous (especially in the case of siblings). Grandparents or younger married couples where adult children are obliged to return home for care, may suffer irreparable marriage breakdown as a result.

Some Possible Solutions and Recommendations

a). Despite painting such a black picture of the average carer's life, it must be clearly recognised that there are almost as many positive as negative aspects. Caring may turn out to be the most rewarding way of life for many people who might otherwise suffer a boring and trivial life style. It forges strong ties with family members, actually improves and deepens many loving partnerships and is a great counter to the modern scourge of loneliness.

b). However carers are NOT SAINTS and have the right and necessity to experience negative emotions and be HEARD. We must all help them to campaign for better social and financial support in return for the unpaid care they donate to keep health and social services running in the UK.

Recommendations

- 1. Carers are significant members of the medical management team and must be kept fully informed and directly involved in all decisions.**
- 2. They should wherever possible, be offered separate consultation and on-going support from the appropriate medical hospital team in charge of the patient.**
- 3. They should be encouraged to have a "separate life" in terms of hobbies, clubs, part time jobs, or other social activities. These will provide essential psychological and financial support both in the present and in the foreseeable future, especially if they can include adult education classes.**
- 4. Patient support groups are of immense importance particularly if they provide "pastoral services" in terms of communication for house or bed bound patients such as interest groups, penfriends and "buddy" services, counselling and educational or other advice as well as telephone helplines.**
- 5. Respite care and "minding" services whether offered by friends and relatives or supplied by social services are an essential "life-line" for patient and carer.**

In conclusion I would like to thank all those carers who have looked after my patients so well and my patients who have cared so wonderfully for me during a long period of home nursing, ended by bereavement - that is what makes life worth living for us all !

**Dr E.G. Dowsett
December 2001**

References

1. Report commissioned by the ME Association and presented on 14.9.91 by DOWSETT E.G. (Chair) and 28 other members of the Working Party on Young People with ME.
2. LEBOEUF C. caring for carers in the Late Effects of Polio, Information for Care Providers, Commonwealth Department of Community Services and Health, Australia 1990; Chapter 15 : 41
3. REES J; O'BOYLE C; MACDONAGH R. Quality of Life : Impact of Chronic Illness on the Partner, Journal of the Royal Society of Medicine 2001 ; 94 : 563-566

Carers Health

The physical health of carers under the age of 65 is a little poorer than others in their age-group . (Welsh Health Survey 1998. Cardiff: The National Assembly for Wales, 1999)

Also, there is a higher chance of "psychiatric morbidity" amongst carers. (Horsley S, Barrow S, Gent N, Astbury J. Informal care and psychiatric morbidity. Journal of Public Health Medicine 1998; 20(2): 180-185)

One study revealed that 51% of carers had suffered a physical injury such as a strained back since they began to care. 52% had been treated for stress-related illness since

becoming carers.

In a survey published by The Princess Royal Trust for Carers (2001), it was revealed that two thirds (68%) of carers currently get no help at all.

The survey revealed that many carers care for long hours, with 22% caring for more than 50 hours each week.

In the UK, 65% of carers suffer ill health or injury !

Another survey of carers revealed that:

- one in five cut back on food;
- nearly one in three have trouble paying household bills and had been in debt;
- more than two in three worried most, or all, of the time about their finances;
- nearly six out of ten had had to give up paid employment to care.
- isolation and loneliness : for some, exhaustion, interrupted sleep and the carer's own ill health prevents socialising with others. A third of carers who spend more than 20 hours a week caring have a limiting longstanding illness, often stress- related;
- lack of services: a lack of services can result in carers having to buy in services or equipment; 59 per cent of carers had used their own income and savings to pay for alternative care;
- exclusion from employment : many carers find it difficult to return to employment because employers are inflexible or unsympathetic.

<http://www.carersinformation.org.uk/topdoc.ihtml?id=61>

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Entitlements

Carers Allowance is the main benefit for carers. Carers Allowance is not means-tested and does not depend on National Insurance contributions.

If you are over 16 and are caring for someone for at least 35hrs a week you can claim Carer's Allowance if they receive Attendance Allowance (any rate) or Disability Living Allowance care component (middle or higher rate); or constant Attendance Allowance paid with a War Pension, or Industrial Disablement Pension AND you do not earn more than £77 a week.

You do not qualify for Carer's Allowance if:

- you earn over £77 a week net i.e. after deducting tax, National Insurance (NI) contributions and half of any contribution you make towards an occupational or personal pension) and after any allowable deductions;
- or you are already getting £43.15 a week or more from certain other social security benefits or pensions such as Incapacity Benefit, Retirement Pension, Severe Disability Allowance or Widows Pension. These are the overlapping benefit rules.

Prior to April 2003 the name of this benefit was called "Invalid Care Allowance". In October 2002 the rules for paying Carer's Allowance changed.

Carers over 65 can now claim Carer's Allowance for the first time. Many pensioners cannot actually be paid any Carer's Allowance because it will overlap with Retirement Pension they receive. However, it is still worth claiming, as they will have an underlying entitlement to Carer's Allowance, which will then entitle them to the carer's premiums on other benefits (principally Income Support). The carer's premium is worth £25.10 a week from April 2003. In some cases this could mean entitlement to Income Support, Housing Benefit or Council Tax Benefit for the first time, or extra money on these benefits if they already get them - **see below**.

NB. If the person you care for receives Severe Disability Premium as part of their means tested benefit, they will LOSE this when you receive your first payment of Carer's Allowance. This means that you get an extra £25.10 a week through the Carer Premium but the person you care for would lose a premium worth £43.15. If not sure whether to apply, ask for advice first.

Carers Allowance is payable for 8 weeks after you cease caring for the person or if you choose not to be a carer anymore, if the person enters hospital or if they die. If the person enters long term residential care, Carers Allowance stops the day that the person enters the care home.

You can seek advice or claim by:

- Telephoning the **Benefit Enquiry Line**: Confidential advice and information for people with disabilities, and their carers and representatives, on the full range of social security benefits available and how to claim them. The line also offers help with claim form

completion for certain benefits.
Telephone 0800 88 22 00
Textphone 0800 24 33 55
Form-filling service 0800 44 11 44

- **Obtaining a claim pack** by completing leaflet DS700 available from post offices, social security offices or your local Citizen's Advice Bureau (www.citizensadvice.org.uk - The national site for the Citizen's Advice Bureaux which includes a list of local sites to help you find your nearest bureau.)
- You can also **download a copy of the pack** from the Dept for Works and Pensions website www.dwp.gov.uk/lifeevent/benefits/carers_allowance.asp - Dept for Work and Pensions information on carers allowance

Carers Allowance, at its current rate (2004) of £43.15 per week, works out at just about 24p per hour - if the carer is caring for 24 hours a day.

You may also be able to claim an additional payment for any Adult or Child dependent.

The Carer Premium

The difference between an Allowance and Premium Allowance ? Some people may be entitled to claim an Allowance or Benefit if they meet certain requirements e.g. Carer's Allowance (£43.15) is paid to people who care for someone for 35 hours or more a week.

Premium Is an 'extra' payment on your means tested benefit associated with some allowances, granted if you satisfy certain conditions e.g. If you are eligible for the Carer's Allowance (£43.15) you may be entitled to an extra £25.10 as a **carers premium** and you may get extra money with any of the following benefits. · Income Support · Jobseeker's Allowance · Housing Benefit · Minimum Income Guarantee.

If you are entitled to Carers Allowance but do not receive it because you are receiving another similar benefit such as the State Pension, you may still get carer premium.

Income Support

You can claim Income Support if you and your partner are on a low income and, for example: - you are caring for someone who is ill or disabled; - you are sick or disabled; you are a lone parent; or - you are registered blind. Partner is used to mean a person you are married to or a person you are living with as if you are married to them. Income Support is a non-contributory benefit. People in the UK who are aged 16 or over, not working 16 hours or more a week, or with a partner not working 24 hours or more a week, and not required to be available for employment, are eligible to claim.

For those who have caring responsibilities, who receive or are entitled to Carers Allowance, a carer premium is payable.

Social Fund Payments

Social Fund Payments can be made for maternity and funeral costs, and for periods of cold weather. Grants and interest-free repayable loans may also help with expenses such as moving into your home. For grants or loans there is only a limited amount of money, so success with an application cannot be guaranteed.

For more information or leaflets, contact your local Social Security office or Jobcentre Plus - listed in the business numbers section of the phone book. You can also get more information from the Department for Work and Pensions website: www.dwp.gov.uk.

The Independent Living 1993 Fund

The Independent Living (1993) Fund can give cash help to pay for personal and domestic care which enables severely disabled people to live in the community. To qualify you must satisfy a number of conditions (see www.ilf.org.uk) or telephone 0845 6018815

HOUSING GRANTS

(Source Disability UK)

Special rules apply for disabled housing requirements, which local councils and landlords are obliged to adhere to. If you are disabled or suffering from a medical condition which requires special housing needs, help is available. Adaptations or alterations to enable you to cope better can be financed by the **Disabled facilities grant**. Your local

housing department should have a booklet published by the Department of the Environment titled 'Housing key facts - disabled facilities grant' and your local social services occupational therapist department can help enormously. Some grants are mandatory while others are discretionary, but if you are refused, there is normally the right to appeal with an independent panel. Grants can be requested by home owners, tenants or a landlord.

Small adaptations such as grab rails, ramps etc. can be provided free from the occupational therapist social services department.

If you find it hard to keep warm in the house due to draughty windows, doors or lack of insulation. Helpful booklets, advice and grants are available from the Winter Warmth Line phone free on **0800 289404**.

You are entitled to an extra room for storage of medical or other equipment relating to your disability. Generally this an extra bedroom or an extension can be built. Grants are usually available for this. If you are a tenant, council or private, the local housing department allows you to upgrade by moving to a bigger house, from say a two to three bedrooms. If you are receiving housing benefit as a private or council tenant, they will pay the extra rent for a house/flat larger than normal.

Carers and Council Tax

There is a possible significant discount available to carers of at least a 25% discount off their Council Tax bills and possibly 50 % in the case of there being two carers. The claim can also be backdated as far back as 1993 and is irrespective of means.

Your Council Tax bill will also be reduced by one band if you or someone living in your house is "substantially and permanently disabled. " and meet certain criteria. For more information on criteria and eligibility, you should contact your local Council Tax department whose address and phone number should be on your latest Council Tax bill - or visit :

www.dss.gov.uk/lifeevent/benefits/council_tax_benefit.htm

State Pension

Your basic state Retirement Pension is automatically protected if you claim Carers Allowance. You will also build up a State Second Pension for each full tax year (From 6 April to 5 April) you are claiming ICA. (Note this only began from 2002). You will be paid State Second Pension as part of your State Pension when you reach State Pension age (65 for men, 60 for women). But after you reach State Pension age, you cannot build up any more entitlement towards a State Second Pension, even if you are entitled to Carers Allowance

If you get Income Support and do not have to sign on, because you are caring for someone, you may be entitled to **Home Responsibilities Protection** to protect your basic state Retirement Pension. You will also build up State Second Pension for each full tax year you are claiming

Income Support. Home Responsibilities Protection (HRP) is not a benefit, but a scheme which helps you protect your basic State Pension. There is more information about the State Second Pension and Home Responsibilities Protection in leaflet PM2 State Pensions - Your guide or leaflet PM9 State Pensions for carers and parents Your Guide. To get a copy of this guide call 0845 7 31 32 33 or visit www.pensionguide.gov.uk.

If you do not work or your earnings are low and you are caring for someone, you may be able to get Home Responsibilities Protection. If you receive Carers Allowance or Carer Premium you will automatically received Home Responsibilities Protection. If you are not receiving one of these benefits but believe you may be entitled, you should contact the Pensions Service for a claim form. For more information call 0845 7 31 32 33 or visit www.pensionguide.gov.uk.

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The **Pension Credit** replaces Minimum Income Guarantee (MIG) and is a new entitlement for people aged 60 or over. It is being introduced in October 2003 although The Pension Service has been writing to existing customers already receiving MIG to tell them about the introduction of the Pension Credit. From October 2003 the Pension Credit will:

People aged 60 or over Guarantee for single pensioners an overall income of at least £102.10 a week and £155.80 for couples; and **People aged 65 or over.**

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