



Cymdeithas Cefnogi
ME & CFS Cymru

Welsh Association of
ME & CFS Support

WAMES needs your help:

- to get a clearer picture of the level of care and support that is available in Wales to both adults and children with ME & CFS
- and a more accurate estimate of the number of patients
- to find out what help carers are receiving

WAMES is the only ME organisation campaigning at a national level in Wales. Your answers to this survey will help us to present the case for services more effectively to the Welsh Assembly Government and others.

Completing the questionnaire:

Please complete those sections of this questionnaire **that are relevant to you**. Circle the appropriate answer to each question and expand your reply in the space provided if necessary.

Contents: 1. Health 2. Social Care 3. Benefits 4. Education 5. Carers

Your name and address are optional, but the County in which you live would help us to campaign more effectively.

- return this form by 30th September 2008 (in the SAE if provided) OR
- download the questionnaire from our website & email it to us OR
- answer this questionnaire over the telephone

This questionnaire will run initially until 30th September 2008 but it will be an ongoing exercise as more patients are diagnosed in Wales. If you have any questions, please contact us at the address at the foot of this document.

The results will be:

- available on our website www.wames.org.uk or on request
- completely anonymous and your details will be kept confidential

**The Patient & Carer Experience:
Survey of ME & CFS Services in Wales**

| | | | | | | | |
|---|-------|--------|-----------------------------|----------|-------|-------|-----|
| Gender | Male | Female | Other | | | | |
| Name (optional) | | | | | | | |
| Address (optional) | | | | | | | |
| County | | | | Postcode | | | |
| Tel no incl. code or mobile no: | | | | | | | |
| E-mail address | | | | | | | |
| Age (If under 25) | | | Date of Birth (If under 25) | | | | |
| Age | 4-11 | 12-17 | 18-25 | 26-39 | 40-54 | 55-64 | 65+ |
| Are you a fluent Welsh speaker? | | | | | Yes | No | |
| Would you be willing to speak to the media in English or Welsh? | | | | | Yes | No | |

1. Health

Who diagnosed you? GP Neurologist Psychiatrist Rheumatologist Paediatrician Self

Other (please specify)

What is your diagnosis? ME CFS ME/CFS CFS/ME PVFS CF

Were you diagnosed in Wales? Yes No Where?

When were you diagnosed?

Do you receive ongoing care? (By this we mean do you receive repeat appointments not that you ring for an appointment when you need to see somebody) Yes No

Who by? GP Neurologist Psychiatrist Rheumatologist Paediatrician District Nurse

Other (please specify).....

Have you chosen not to discuss/ continue discussing your ME with your doctor? Yes No

If yes, Why? s/he does not have the knowledge to help me

s/he made it clear she does not believe that ME is a valid illness

I was made to feel that I was a malingerer

s/he was rude and/or hostile

Other (Please state).....

What ability level would you say you were?

Mild (mild symptoms after activity, able to work or study, but need to take care)

Moderate (symptoms ever present but worse after activity, lifestyle much reduced)

Severe (symptoms always a problem, very limited activity, mostly housebound)

Very severe (symptoms severe, mostly bed bound & needing help most of the time)

or a mixture - please state:

2. Social Care

Have you approached your local Social Services office for help? Yes No

Do you receive any social care help? Yes No

What kind of support are you offered? (Please specify).....

If you were refused were you given a reason why? Yes No

What reason were you given? (please specify).....

Have you been offered Direct Payments? Yes No

Have you been prescribed any aids to help you?(Please specify) Stairlift Wheelchair Walking frame Commode

Other (please specify).....

If ill since childhood were you referred to Child Protection? Yes No

What year? (please specify)

Were you placed on the Child Protection Register? Yes No

3. Benefits

Have you claimed Disability Living Allowance? Yes No

Were you turned down for Disability Living Allowance? Yes No

What reasons were given? (Please specify)

Did you appeal Yes No Were you successful? Yes No

Have you claimed Incapacity Benefit? Yes No

Were you refused Incapacity Benefit? Yes No

Did you appeal Yes No Were you successful? Yes No

Have you had any problems in claiming other related benefits such as Income Support/Housing Benefit/Council

Tax Relief? Yes No

4. Education

Are you too ill to go to school? Yes No

Have you been offered home tuition? Yes No

Have you been refused home tuition? Yes No

Have you been offered e-learning? Yes No

If appropriate do you receive exam concessions? Yes No

What concessions were arranged for 2008 exams?

Please specify.....

Are you able to attend school or an FE college? Yes No

Have you made yourself known to the Special Needs Co-ordinator? Yes No

What concessions have been arranged for you to enable you to attend?

Taxi Reduced timetable Laptop Dictaphone Scribe Exam concessions

Other (please specify).....

Are you able to attend University? Yes No

Have you made yourself known to the Disability Officer? Yes No

Have you been offered any help? Yes No

What help has been offered? (Please specify).....

5. Carers

Gender Male Female Other

Name (optional).....

Address (optional).....

.....

County Postcode.....

Tel no incl. code or mobile no:

E-mail address.....

Age (If under 25)..... Date of Birth (If under 25).....

Age 4-11 12-17 18-25 26-39 40-54 55-64 65+

Are you a fluent Welsh speaker? Yes No

Would you be willing to speak to the media in English or Welsh? Yes No

Are you a carer of a person with ME, CFS or PVFS? Yes No

Is this an adult or a child? (Please specify)

Have you approached Social Services for help? Yes No

Have you been offered a Carer's Assessment? Yes No

Do you receive any services as a carer? Yes No

If answered Yes to above question what services do you receive? (Please specify).....

.....

From whom do you receive services? i.e. Social Services or private arrangement. (Please specify).....

.....

Do you receive respite care? Yes No

Is this arranged by Social Services? Yes No

If No who provides you with respite care? (Please specify).....

.....

Have you claimed Carer's Allowance? Yes No

Do you receive Carer's Allowance? Yes No

Have you needed to give up work to continue caring? Yes No

If you are able to continue working has your employer made allowances for your caring role? Yes No

What allowances have you been granted? late start early finish part time

Other (Please state).....

Please return in SAE (if provided) or to:

Sylvia Penny
58 Greenfield Avenue
Dinas Powys
Vale of Glamorgan
CF64 4BX

E-Mail Sylvia@wames.org.uk

Tel: 029 2051 4328