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CAMBRIDGESHIRE AND PETERBOROUGH
CHRONIC FATIGUE SYNDROME/ME SERVICE
PRE – CLINIC QUESTIONNAIRE

PLEASE COMPLETE DETAILS IN CAPITALS:

NAME: **Mr Paul Daniel Carpenter**

ADDRESS: **Seven Acres, Gull Drove, Guyhirn, Wisbech,
Cambridgeshire PE13 4BH**

TELEPHONE NUMBER: **01945 450807**

DATE COMPLETED: **Wednesday 1st November 2006**

Bold Blue How I feel Now Bold Red differences Six weeks ago

Before attending the clinic, please complete the questionnaire. It might be useful to have a partner or friend to help you. Question 1 allows you to describe how the illness started. The other questions give you a choice of answers and a space to add comments if you wish. Please tick the response which fits best. There may be more than one response per question.

There is currently quite a lengthy waiting list within the CFS/ME service; it is therefore, most important that you return this questionnaire to us with the shortest possible delay, so that you can be seen as soon as possible. Until we receive this questionnaire we will not be able to issue you with an appointment.

If you are unsure of how to answer a question or you do not understand a question, please telephone Sarah ##### on 01733 ##### the service Administrator. If however she is unable to deal with your query it will be given to Dr. Mitchell or one of the team to deal with.

Do not feel obliged to fill up all the space left for your comments. If you do want to write more please do so on a separate sheet of paper.

Many Thanks.

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QUESTION 1 – Brief History.

Could you tell us how the illness started and progress, i.e. getting better/getting worse/about the same. Please include the date of onset if possible. Did you have a 'virus' at the start of the illness and were you under any stress? Are you still at work or when did you stop work?

Write your answer in the space below:

My illness started in November 1987 aged 23 with a sore throat and flu symptoms this lasted approximately 4 weeks and I continued working during this time.

I was working as a Self-employed IT Contractor in the City of London my work was both physically and mentally challenging as it included responsibility for planning and executing office moves at weekend and evenings involving upto 40 people and all their IT equipment.

The flu symptoms and sore throat subsided and I became increasingly fatigued and unable to work with a general all over headache and sensitivity to light and sound.

I had an ache in my lower back about the kidney area and other muscle and joint pains which moved around I was drinking a lot of fluid and basically stayed in bed for about 6 months, with occasional good days when I was able to go out for short periods.

Memory and concentration were completely gone I often found myself staring into space and unable to remember what I was about to do half way up or down the stairs.

Occasionally when really bad I was unable to move my left hand and arm and had a very strange feeling where my bones felt like rusty metal/barbed wire and my body felt like jelly or dough covering the rusty metal this would last anything from 10 minutes to a couple of hours.

I saw the doctor on a regular basis but was considered to be suffering with depression and given anti-depressants which had no effect.

In May 88 I changed doctors and was given a complete examination at which point a lump was detected in my neck and hodgekinsons was suspected – my parents arranged a private appointment and I was admitted to hospital within 2 days to have the lump removed.

It was found to be a reactive lymph node and assumed to be as a result of a virus possibly Glangular fever.

Within 6 weeks of this operation I was back at work initially part-time and full time within 4 weeks.

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Approximately a year later June 89 it started again in a similar way but no lumps were found and again I was unable to work and all the symptoms returned – at that time yuppie flu was the term used and I fitted this as an IT Contractor working in the City of London.

After about six months of getting nowhere either with the symptoms or the medical profession my parents arranged a private appointment with an acupuncturist and homoeopathist after 3 months of treatment I was able to return to part time work and subsequently full time.

Since this time I have had periods during colds where all the symptoms return but generally this has not lasted longer than a month or 6 weeks but has prevented me from working during those periods.

Also when tired or stressed the symptoms do return from time to time approximately 2-4 days every 1-2 months.

The last major episode with all the symptoms returning started in October 2004 and has lasted 2 Years, until about 6 weeks ago.

At its most severe it starts with overheating I cannot speak, I cannot think and I have uncontrollable shaking and twitching I cannot move as I am unable to cope with my surroundings, external stimuli and completely disoriented this lasts from 5 – 20 minutes and is a new symptom of the latest episode with the last occurrence about 4 months ago.

About 6 weeks ago I decided to look at the major problem logically i.e. lack of energy the malfunctioning of the bodies aerobic energy system and researched into what could help.

I came across 2 amino acid supplements one of which is given to patients in French hospitals to aid recovery after operations (L Ornithine Alpha Ketoglutarate) the other recommended for athletes and body builders to aid exercising and recovery (L Glutamine)

I have now been taking these supplements for 6 weeks and am almost what I would consider back to normal!

I am currently taking 3 times daily in fruit juice: -

A mixture of L Glutamine & L Ornithine Alpha Ketoglutarate 3g

and so far haven't noticed any side effects - apart from what I would consider near normal energy levels.

If I am extremely busy such as a whole day of DIY (Proper DIY - Plastering, cementing, Tiling, Plumbing, Coving, Painting - any one of

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which I was previously unable to do without at least a weeks rest before and after and then only for a couple of hours) I have found that an additional dose at night helps my energy levels for the next day.

QUESTION 2 – Diagnostic Criteria

Please tick the answer which fits your symptoms

- **Memory and Concentration**

- a) My memory is
- Normal
 - Worse than before I was ill

Yes	No
Yes	No

If your memory is worse, is the loss

- Slight
- Moderate
- Severe

Yes

Write your comments in the space provided:

Struggle to find words in normal speech, slowness in speech and a reduction in conversation, can't remember what I was about to do – loose complete days where I don't remember what I did – probably asleep.

- b) Concentration
- Can you read a book normally?
 - Do you have problems with mental Arithmetic?

Yes	No
Yes	No

Please complete the following by adding the length of your concentration span, i.e. how long does it take you to get mentally fatigued:

My concentration span on a good day is 60 minutes.

My concentration span on a bad day is 0 minutes.

Write your comments in the space provided:

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- **Do you have recurrent sore throats?**

Yes	No
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Write your comments in the space provided:

To the point where my voice became croaky and lower for 3 months about 6 months ago.

- **Do you have tender or enlarged glands (lymph nodes) in the ;**

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Neck **SomeTimes** Groin **None**
Armpit

• **Do you have muscle pain?**

None **Yes** Mild Moderate **SomeTimes**
Severe

If muscle pain is present where is it most?

Arms Legs Back Neck

Write your comments in the space provided

Around the kidneys/lower back area.

• **Do you have joint pains?**

Yes **No**

If yes, which joints?

Feet **Yes** Ankles **Yes** Knees **Yes** Hips **Yes**

Shoulders Elbows **Yes** Wrists **Yes** Hands **Yes**

If yes, are the joints stiff in the morning?

Yes **No**

Did you have joint pain before this illness?

Yes **No**

**** Please distinguish between muscle pain and joint pain if possible****

Write your comments in the space provided

The muscle pain is like mild cramp like I've been exercising too much. Joint pain is probably the wrong description it's neuropathic pain more nerve based and primarily in the hands, fingers and forearm.

Occasionally right in the funny bone and only my left elbow, very severe lasts from 10 to 30 minutes.

Feet are very stiff and moderately painful in the mornings for about 30 minutes.

Pains move about and can occur anywhere including eyes, nose, ears, face – just about anywhere!

I still get some pains but they are much reduced in number and level and 30mg of Amitriptyline normally helps within about half an hour.

• **Sleep pattern – are you sleeping normally?**

Yes **No**

If the answer is no, which best fits what is wrong:

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Difficulty in getting off to sleep
Constant waking during the night
Waking up early
I wake up feeling as tired as when I went to bed

Yes
Yes
Yes

Are you taking sleeping tablets, if so what are they called?

No medication **No** My current sleeping tablets are:
Sleeping for extended periods of time as much as 16hours without waking and difficult to rouse.

• **Headache- do you suffer from headaches?**

Yes	No
-----	----

Did you have regular headaches before you came ill?
Have you ever suffered from migraine?

No
Yes

If yes, please describe the attacks

Write your comments in the space provided

Migraine once about 6 Months ago April 06 – Broken vision left eye headache over left eye then moved to back of head – repeatedly sick and disorientated lasted one day and night complete fine next day.

If you have new headaches, i.e. starting with this illness and different from previous headaches, where do they occur?

Front of the head, over the eyes

 Yes

Top of the head

 Yes

Sides of the head (which side)

 Both

Back of the head and neck

 Yes

Left/right/both (please circle)

Please describe

All of the above no particular pattern dull pain most days don't take too much notice. Sometimes tense when back of head and neck.

Would you describe a headache as a:

Sharp pain

A dull aching

 Yes

Tense etc

 Yes

Please describe

Back of head and neck are tense elsewhere dull ache –some of this could be attributed to my use of the computer.

Do ordinary headache tablets help?

Yes	No
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If no relief, can you list the medication tried so far

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Write your comments in the space provided

Paracetamol, Codene, Anadin, Aspro Clear used to help.

- **Can you describe what happens if you push yourself too hard, i.e. how you feel and which symptoms are worse?**

Write your comments in the space provided

At the moment no real problems.

Rapidly become exhausted and need to rest – increase in pains – disoriented and totally indecisive – if out find it difficult to cope with bright lights supermarkets particularly difficult, colours too bright particularly green makes me feel sick – get shakes and twitches – overheat – takes several days in bed to recover. Cannot cope with objects moving across vision left to right or vice versa – feel sick if in car and look out side window objects blur unable to focus.

QUESTION 3 – Other Symptoms

Individuals with chronic fatigue/ ME often have a wide range of symptoms, some of these are mentioned below.

- **Do you have a problem with:**

Nausea (feeling sick)?

Yes	No
Yes	No

Vomiting (actually being sick)?

- **Has there been a change in how your bowels work?**

	No
--	----

If yes, please describe what has happened

Write your comments in the space provided

- **Do you have a problem**

Passing urine

No

With 'cystitis' symptoms

No

Incontinence (urine leakage)

No

Write your comments in the space provided

- **Do you have a problem with temperature control?**

- Cold hands and feet (not previously present)

Yes	No
Yes	No

- Inappropriate response to temperature

E.g. hot in a cold room or cold in a hot room

Write your comments in the space provided

Mostly too hot especially when active very easy to overheat regardless

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of external temperature - always warm hands.

When bad the opposite in that regardless external temperature feel cold and shivery going to bed in tracksuit, socks, jumper and even a woolly hat.

Please add any other symptoms that worry you. Describe them in the space provided below.

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QUESTION 4 – Activity Levels

Please select one of these two statements:

- a) I have good/bad days or periods
- b) Every day is much the same

Yes	No
Yes	No

Please describe a bad day, i.e. what time do you get up, can you wash/shower, how do you feel afterwards, and what can you do during the day. Please give as much detail as possible for each period of the day. **BAD DAY** if you answered 4a or **AVERAGE DAY** if you have answered 4b.

Morning

Generally asleep only get up to use toilet and takes several stages/Attempts to get there – Making decision – sitting up and getting half out of bed – standing and walking there – toileting – getting back to bed collapse on bed – get back into bed.

May get up to eat again in stages.

Afternoon

Same as morning.

Evening

May be able to get up and watch TV for a hour then back to bed and sleep.

Loose structure difference between day and night. Might sleep all day and be able to briefly get up at night, whole days blur together.

Please describe a better or good day in the same was as above. **BETTER DAY.** (If your days are much the same there is no need to fill in this section)

Morning

On a good day I can be almost normal get up about 7 eat breakfast have a shower. Go downstairs and work on the computer or do some light DIY.

Sometimes it starts off ok and then after the shower I'm completely worn out and collapse on the bed and fall asleep for 2 hours then I can continue but slower than I started.

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Afternoon

Eat lunch 12:30 – 13:00 – generally quite tired after this and sleep for about 2 hours. Then probably watch TV or use computer.

Evening

Eat about 18:30 again can be tired and sometime sleep for what I think is an hour an hour (actually 2-3 or more) then watch TV and go to bed about 22:30.

How many good days do you get in a week (0, 1, 2, 3, 4, 5, 6, 7)

7 2

How many bad days do you get in a week (0, 1, 2, 3, 4, 5, 6, 7)

0 5

If there is a different pattern please describe below:

Sometimes I can have 5 Good Days but this is generally followed by 10 or so bad days.

Can you describe, in terms of activity, an average working day **before** you became ill, i.e. how many hours at work, including work in the home, time spent on family duties, time spent on hobbies/sport etc.

Write your comments in the space provided

Very active worked 10-12 hours including travelling then hobbies and other activities including DIY and farming walking dogs etc

Can you describe what you were like before you became ill, e.g. life and soul of the party, bouncy, sporty, outward going, always a worrier etc? Often a friend or partner may be able to prompt you with this question.

Write your comments in the space provided

Very active and outward going. Enthusiastic, creative, inventive, strong conversationalist – keen to be involved in local community.

How far can you walk on a good day?

Less than 50 metres

Greater than 100 metres

**Yes
Miles**

Do you often use a wheelchair?

Yes No

If yes, can you describe the circumstances, e.g. in the house, just going shopping etc.

Write your comments in the space provided

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QUESTION 5 – Medication

Can you list the names and doses of the tablets you are taking at present (or attach a list supplied by your own GP?)

Amitriptyline started on 10mg increased to 30mg now only occasionally when pains return. Twice in last 14 days.

Started on 10mg and gradually increased to 30mg Amitriptyline everyday for last 8 Months until 6 weeks ago late September.

QUESTION 6 – Mood

In the past have you ever been depressed?

Yes No

If yes, describe when, and what were the circumstances, i.e. post natal, relationship problems, out of the blue, etc.

Write comments in the space provided

Pissed off, Frustrated, annoyed, irritated, irritable and definitely irritating but never depressed.

Did you receive medication?

Yes No

If yes what was it?

Did the medication help?

Yes No

If you had medication did it give you side effects?

Yes No

If yes, what were they?

- How would you describe your present mood

Normal

Yes

Low

Swings in mood

Irritable when tired

Yes

Frustrated

Yes

Suicidal

Write your comments in the space provided

Have experienced negative thoughts during extended periods of illness.

- Has your GP tried anti depressive medication in this illness?

Yes No

If yes, did the medication help you?
Did you have side effects?

Yes No

Yes No

If yes what were they and what was the medication called?

Write your comments in the space provided

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Amitriptyline 10-30mg

- Have you ever suffered from anxiety in the past?

Yes	No
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If yes, can you describe the symptoms, e.g. palpitation, irritable, over breathing, sweating etc?

Write your comments in the space provided

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QUESTION 7

Can you please respond to the following set of statements? This will give some idea how you are reacting to your illness. The response to any chronic illness such as chronic fatigue syndrome/ME can be very important in putting together a treatment package to help you stabilise and overcome the problem.

Please try and complete question 7 in 'one sitting' if possible, do not take too long over your replies as your immediate reaction is probably correct. Just tick the response you thinks fits best.

Only one response per statement please.

- I feel tense or 'wound up'

Most of the time	<input type="checkbox"/>	A lot of the time	<input type="checkbox"/>
Occasionally	<input checked="" type="checkbox"/>	Not all the time	<input type="checkbox"/>

- I still enjoy the things I used to enjoy

Definitely as much	<input checked="" type="checkbox"/>	Not quite so much	<input type="checkbox"/>
Only a little	<input type="checkbox"/>	Hardly at all	<input checked="" type="checkbox"/>

- I get a sort of frightened feeling as if something awful is about to happen

Very definitely, quite badly	<input type="checkbox"/>	Yes, but not too badly	<input type="checkbox"/>
A little, does not worry me	<input type="checkbox"/>	Not at all	<input checked="" type="checkbox"/>

- I can laugh and see the funny side of things

As much as I always could	<input checked="" type="checkbox"/>	Not quite so much now	<input type="checkbox"/>
Definitely not so much now	<input type="checkbox"/>	Not at all	<input type="checkbox"/>

- Worrying thoughts go through my mind

A great deal of the time	<input type="checkbox"/>	A lot of the time	<input type="checkbox"/>
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Not too often Very little **Yes**

- I feel cheerful

Never Not often
 Sometimes **Yes** Most of the time **Yes**

- I can sit at ease and feel relaxed

Definitely **Yes** Usually
 Not often **Yes** Not at all

- I feel as if I am slowed down

Nearly all the time **Yes** Very often
 Sometimes Not at all **Yes**

- I get a sort of frightened feeling like 'butterflies' in the stomach

Not at all **Yes** Occasionally **Yes**
 Quite often Very often

- I have lost interest in my appearance

Definitely I may not take quite as much care
 I don't care as much as I should I take just as much care as ever **Yes**

- I feel restless as if I have to be on the move

Very much indeed **Yes** Quite a lot
 Not very much Not at all **Yes**

- I look forward with enjoyment to things

As much as I ever did **Yes** Rather less than I used to
 Definitely less than I used to **Yes** Hardly at all

- I get sudden feeling of panic

Very often indeed Quite often
 Not very often Not at all **Yes**

- I can enjoy a good book or radio or television programme

Often **Yes** Sometimes
 Not often **Yes** Very seldom

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QUESTION 8 – Past medical history

- What physical illness, e.g. asthma have you had in the past. Have you had any operations?

Write your comments in the space provided

Two operations on my ear which was perforated with discharge and infection in bone behind ear at age 9/10/11.

Part of Cartilage removed left knee aged 16.

Lymph Node removed from neck aged 23.

3 Wisdom teeth removed Feb 99 aged 35.

- Have you ever had an illness, similar to this one after a virus or when you have been stressed?

Yes **No**

If yes, please state when and where etc.

Write your comments in the space provided

All symptoms return when I am stressed or have any other illness mainly colds/flu.

QUESTION 9 – Your view of the illness

- Do you think you have chronic fatigue syndrome/ME?

Yes **No**

Do you feel you may have some other illness as yet undiagnosed?

Yes **No**

If yes please share your worries

Write your comments in the space provided

After over twenty years I just want this to stop so I can get on with all the things I want or need to do!!!!

- Please answer one of the following questions

Do you feel that this illness is physical?

Yes **No**

Do you think the illness is a mental problem?

Yes **No**

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Do you think it might be a mixture of both physical and mental?

Yes	No
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Please feel free to add any thoughts you might have on the last three questions

Although this illness has symptoms which affect my mental functioning I am convinced it is entire physically based/caused.

QUESTION 10 – What would you like us to do most?

- Give a firm diagnosis?
- Exclude other illness?
- Relief of specific symptoms?
- Advice on the best way of managing the illness
- Other (please state)

Yes	No

Write your comments in the space provided

I feel the Amino Acid supplements I'm currently taking are working and worth further clinical investigation.

Find a cure or at least an effective treatment.

We should like to thank you for completing this questionnaire. We realise it may have been very exhausting and may have taken some time. It will however enable us to focus more precisely on the nature of your problems and the possible way round them when we meet in the clinic.

28 August 2002
ME directory: questionnaire