Exploring the Relationship between Service-Users' with CFS/ME and NHS Professionals

Addendum

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Notes

All identifiable factors were removed to protect the participants' anonymity and all participants were given pseudonyms.

The transcription convention outlined below is based on Burman's\(^1\) convention.

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Speech that is less than three words per person is included in the same paragraph as the person speaking immediately before the present speaker.

Speech marks are used when a participant retells a conversation or acknowledges a thought.

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I: To begin with, I am interested in exploring your relationships with health services. I am particularly interested in aspects that you have found helpful or unhelpful in terms of the services you have received to date. I will also be looking at the way you manage your symptoms. Does that seem okay? Perhaps if I tell you what I am doing with the information. (2) I will be transcribing our discussion today and I will be using qualitative analysis to generate themes from the data. I will be doing four groups with four different people.

Tom: Will we see any results of this in time?

I: Yes my hand-in date is June, and I may have a Viva (which is basically a meeting with two people who will moderate my thesis) and I may have my Viva in September. I am aware that I said I would present the results to all participants in August. However it may be better to wait until after the Viva to do this. I think what I will do is ring up all the participants and write to you again to arrange a time and date to meet to present the results.

Steven: Or I guess another option would be that if you produce a short summary. A written summary, that might be easier instead of trying to get everyone together again.
I: Yes and it is quite a way for some people to travel.

Steven: Of course do what you think is best. It depends on what other people want.

Jessica: I don't know, I would also like the chance to meet a couple of people who have also got ME. Well, I am also not travelling 20 plus miles, I think that makes a big difference myself.

I: Well what I think I will do, is produce a short report and then contact people to see if they would want to come to a presentation, so at least you have the option.

Tom: When you have got all the information you want, what is the overall goal? What is it supposed to do?

I: The idea of the kind of analysis I am doing, is that you get a theoretical model that is based/grounded on the information that is generated in group discussions.

Tom: And that's supposed to help health professionals, doctors etc?
Focus Group 1: 4th March 2005 at 2.00pm.
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I: Yes I will be feeding back to the CFS Service. I will also be looking at publishing the research in a peer review journal.

Tom: Right, so that might improve treatment plans, and stuff like that.

I: If anyone has got other suggestions of ways in which I could disseminate the results I would welcome suggestions. (3). I will be of course removing all identifiable information from the transcripts, by this I mean names places and any professionals that are referred to. Has anyone got any questions they would like to ask about the research? (4). I have already mentioned a little bit about confidentiality, I would like to suggest that we agree on some ground rules for our discussion today. I feel it is important that we agree that everything we say today remains in this room, and is not talked about to other people outside of the group.

[All members nodded in agreement]

I would like to hand out a consent form. This form basically says that you have had the opportunity to discuss the research with me, that you agree to the discussion being taped, and that excerpts of the group discussion may be used in my write-up.

[Consent forms handed out and pens given to each member]
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Jessica: Was the Information Form the thing that you sent out to us?

I: Yes.

[(34) The group members completed the form]

Steven: I have just put the wrong date, it shows what my brain is doing today. Oh dear me. [Sighs exasperatedly]. I will scribble it out and do it again.

I: Okay. Shall we make a start? What term would you prefer me to use, ME or CFS? Have you got any preference?

Jessica: Well I normally use ME, as this is shorter and quicker. [2 members laughed]

Julie: I normally refer to it as CFS.

Tom: Yes I know it as CFS.

Steven: CFS tends to be, yes I mean, I am not bothered either way to be honest, whatever suits.

I: I usually say chronic fatigue I am a bit lazy and don't use syndrome. [Laughing]
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I: Okay. A good place to start is to think about how would you describe CFS to a person who did not know what it was?

Jessica: I have got two ways of doing it. One of my friends is actually a doctor in hospital, so very recently I tried to explain to her what really tired means, and that actually the word tired isn’t what you should think of. And she said, “Oh is it like when you have been on call for 24 hours and you haven’t slept and you don’t care about anything that isn’t here”. Jessica held up her hands vertically on either side of her eyes as if to motion that you cannot see anything that isn’t right in front of you]. Which is not a great explanation but…

Julie: At least it shows she understands.

Jessica: At least the best one I have come across is have you ever had glandular fever?

Julie: I use flu.

Tom: Yes I use flu.

Julie: Because I have never had glandular fever.
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Tom: Yes it’s just like the onset of flu, but it’s there all the time. (I: Right)

Julie: Because that is what I thought I had to begin with. It’s like you ache all over all the time. Whatever you are doing you know if you are able to lie down comfortably. (I: Right).

Whatever the time of day or night, given the opportunity I will be able to sleep.

I: Right. I guess that’s a really good way of portraying that to people as most people have had flu. Would you agree [directed at Steven]?

Steven: Oh yes, yes sure. I was just thinking, I suppose, I mean the fatigue is not the most, erm, interesting symptom from the point of view of diagnosing the condition, because everybody has fatigue. For me, one of the big problems is the cognitive effect, the fogging – mental fog, short-term memory, [agreement acknowledged by Julie and Tom],

Julie: short attention span

Tom: problems of words …

Julie: Yes I struggle to get my words out…
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Steven: ehm problem with finding words. It’s the cognitive

side which is, ehm, more ehm (2)

Jessica: Troublesome?

Steven: Yes more troublesome but also the side, which

perhaps is hard for people to get a handle on because yuppie

flu you know is... [Tom laughs]. It’s just people are tired,

you know and so you forget there is a whole range of other

things. The pain, the pain discomfort side is also, something

which is- I am fairly fortunate I am not in severe pain but I

know some people with this condition, who are dosed-up on

pain killers all the time because of muscle pain and joint pain

or a combination of the two. So that is, that can be a

significant part of the syndrome for some people.

Jessica: I think the thing I find really, it’s, when you are

talking about the cognitive stuff - is when you like you have

forgotten where your keys are for the tenth time that day and

you are going, I can’t find them, I can’t find them and I get a

bit stressed these days about it. (Tom: Yes, yes). Because it

kind of makes me feel sick, because of the number of times I

have spent half an hour looking for my keys when they are

exactly where I put them and I can’t see them when I look at

them sometimes. And people are like, oh yes that happens to
me all the time and you are like no, no no, there is a
difference between it happening once a week or once in a
while to this many times a day and people don't get when
you start to get stressed, or when you are struggling to find
the right word, and they just think well everyone struggles to
find the right word occasionally. (I: right). But when it's
like, all the time...

Julie: And it, what, for me was a problem is that yes some
people do have these problems with words and memory but I
didn't used to. (Tom: ehm). Up until 18 months ago I didn't
have those problems I was very articulate in my job...

Jessica laughs in agreement]. Someone could ring and ask
me a question and I would have the answer. Now I'm having
to say I have got to go away and look it up. (I: right) And I
am having, I could read things and that's it I'd got it but now
I'm having to read and re-read and highlight it and make
notes and (2) you know these things- for somebody who asks
what's the problem. Yes I'd explain the physical side
because that's the easiest thing for them to understand. (I:
ehm, yes). The other side, yes if they hadn't known me
before they wouldn't know there was a problem (2) but I
know that there's a cognitive problem there and people that
knew me well before, know there's a problem there. (I: Yes).
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Jessica: Yes – one thing is there are some symptoms I don’t feel comfortable telling other people about I don’t mind chatting to my other friends about it who have got ME about it. But one thing I used to get, well I still do to some point is that my bowels are not under my control any more [she laughs] so I can have constipation and the next second like diarrhoea. Well if I am feeling like that, and my lecture isn’t, wasn’t near the toilets it would be like well I can go to the lecture and risk shitting myself [laughing] or I can skive the lecture and stay near my toilet. And frankly the toilet seemed more important. And it is like when tutors go well why were you not here, it’s like well who would really fancy sitting there next to me, pooping myself [she laughs, then all participants laugh]. You know it’s, it’s kind of, it’s just there’s so many different things. I mean one of the problems I’ve had, this is a slight digression is that I have actually had another very serious illness. And they didn’t know I had a brain tumour simply because ME has so many symptoms, I mean just about every symptom in the world seems to be part of ME. But they didn’t notice it coming until I was laid up in bed hallucinating and unable to walk straight. It, you know was literally last minute, “oops”, [laughs], “better get her into surgery now”. It’s just like, you can’t go to the doctor every time you develop a new symptom. I feel like I see my doctor plenty. I mean I’m sure he is fed up with the sight of me
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[laughs]. But what do I do, I mean I now know, don’t know what to tell the doctor and what not to, because when I started seeing things it’s like well yeah there was a cat wandering around my bedroom there was an alien hovering in my, you know hallway in the night. That’s not unusual that’s been happening for 10 years. So, I you know, and the doctor was like, “Well if you’d said that I would have been worrying”. And that like, but it’s been around for, you know what I mean?

Steven: Yes I think you are absolutely right, I mean part of the problem is knowing what is the appropriate level for the alarm bells to start ringing because you keep getting, this is what’s so frustrating you think you have dealt with one set of symptoms like I was getting exceptionally bad IBS problems, you know like diarrhoea you know sort of fifteen times a day. Got that sorted out and then started from Tinnitus. So you know you are immediately into the so well what’s going on here. And you keep, you have to, you periodically go back to the GP and it’s back to the, well you know is this something serious or is it just part of the same syndrome? (I: Right). And nine times out of ten or hopefully you know more than nine times out of ten it is just part of the process of the condition – it doesn’t do your self-confidence any good because you are continually presenting new symptoms
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[Laughs].... (Tom: I, I...) [Finishes laughing]. Sorry go on.

Tom: I did a lot of research on the net and depending what sites you looked at, ehm, some gave more comprehensive lists of symptoms than others. (I: Yes). Because when I went to my doctor, she said it was Labyrinthitus at the start where I was sort of giddy and things like that and sick and then the tiredness hit me and really just extreme tiredness all the time and I thought you know I am not go along swapping one symptom to another and one label to another rather. So I did a lot of surfing on the net and just like you said you know other symptoms keep coming, I was a bit prepared for that, you know, because at such and such a site someone had already mentioned that. (I: Right). Ehm and with all these things, its easy to say, but you've got to stay positive and you got to try and help yourself. Ehm cause my doctors been very supportive considering I have resisted almost every attempt to take any medication because I react very strongly to drugs anyway, and I thought I'm not having that on top of what's already going on. (I: Yes, yes). But she has been very supportive (1), and said that if I change my mind on that she will try different things. So I did. But things like Prozac, ehm and stuff to try and combat the sleeplessness Diazipine or Diazepam or something like that. Ehm, I just didn't want to become someone who was chucking drugs in to keep
treating these symptoms and in the end I thought, well I will
just live though it and find ways of just accepting what’s
there.

I: It almost seems like, what you’re saying, and please tell
me if I’ve got it wrong, but I think Jessica you were saying
that just about every symptom is involved in CFS. Checking
up on it, it seems that different websites tell you different
symptoms, and it just seems that there’s so much uncertainty
about what may come next and what does it mean? So I’ve
got this symptom now. And as you said Steven about your
self-confidence takes a real knocking when that starts
happening and you have to…

Steven: Well, let’s be honest about it there’s an also an issue
of personality here. It is known that ehm that people who get
this condition tend to be more control freaks than perhaps
people who don’t. It doesn’t mean that it’s a psychological
condition, it just means that we tend to be people who are
perfectionists and people who are used to being in control of
our own lives. So, this kind of condition is very difficult to
cope with because of that—because it takes away that degree
of control that you have so you are caught up in trying to sort
of go on as business as usual. Whereas the reality is your
body is not allowing you to do that.
Jessica: But you can't trust your own senses. You know I was going through this thing when nothing tasted right.
When I have had Tinnitus, I have been like in the night going, "Ooh is that my alarm clock?" Cause it beeped, you know I was using my phone and I was hearing ringing beeping in my ears and I wasn't sure if that was the Tinnitus, sort of thing, so I would wake up pull the ear plugs out and go Nope level hasn't changed must be Tinnitus then, you know [Tom & Steven agree] which disturbs your sleep erm, when you are seeing stuff, you think the cat's out, but you keep seeing this black thing out of the corner of your eyes fluttering around and it's just like it gets to the point where you know, I have been at crossings, seen the light change, stepped out to have drivers swear at me because the lights haven't changed, and I step back and the next time it's changed there has been a light and a noise and you are like, shit okay, and it makes crossing, you know, it comes to something when even crossing the road you can't be sure, you just can't! And It's, (2) I don't have words for it, I can't explain this to anybody. You know it's like.

I: I think actually from what you have all said, flu doesn't seem to touch it now really...
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Julie: No, flu is (2) it's the physical feelings.

Tom: Yes it's the physical

Julie: There is so much more. When I finally erupted in front of my doctor, well this isn't the only symptom, this is happening, this is happening, this is happening and I finished with I am increasingly getting bad hangovers on an ever decreasing amount of alcohol. [And everyone laughs].

(Steven: Yes, yes).

Tom: I think the confidence thing is, erm, I expected it to have like, when it first happened it was like flu, couple of weeks off work I'll be alright. But when it went on and on, the first time you encounter someone who doesn't believe you, erm or maybe its in your own mind you know that, someone thinks you are making more of a meal of it, that's when my confidence got knocked. (I: Right). And unfortunately it was close to home because my wife at the time hadn't been having a good time so when you feel doubted you begin to think well am I making more of a meal of it. And then you go through, I think my first lucid spot as I call it was like, I was back to normal, I woke up, my energy was back so I started doing things like normal, big mistake [laughs]. 'Cause you know that day later I paid for it and paid
for it about a week or so. You know I really went back to really heavy symptoms. Erm, so that was like something I had to deal with, and it was almost as bad as the stuff itself, as it was, explaining to people actually no I know this is going on a long time but I am not putting it on and I don’t have the control over it that I would like. Then having to be, I mean sometimes I’ve been from my way seeing of it pretty bloody minded because I just think “no I’ve got to set some parameters where I operate- and if people think I’m being selfish its tough because if I go beyond them too much down I go”.

I: So it’s a learning curve? (Tom: Yeah).

Jessica: I’m much more careful with friends now as well I mean for me its been a long time I was diagnosed in 1991, and in that time I have had friends, who you know, when I have been managing it well, I get, I know that I could go away for the weekend and as long as I sleep really well I can be a bit stupid and then for the next week or two I will be very tired, very in pain and everything will be up the creek. And then she would go around telling people “I know she’s all right because I’ve seen her”. [Group agreement] forgetting that you know that if I’m feeling really ill you don’t see me because I can’t cope with that I can’t cope with somebody in
the house. If just the slightest noise reverberates around my
head and feels like lots of people not, and you get confused
by more than one noise at the same time. You know,
sometimes friends will be like, "Oooo I'll have music on",
while we chat and I'll be like, "No please don't". (Tom: Do
you get...).  

Julie: We have this thing with the television cause my
boyfriend turns it up, and when he goes out the room I turn it
down. [Laughs] And he comes back in and turns it up.  

Tom: Do you get noise sensitive? (Jessica: Sometimes
yes). And light sensitive as well? (Jessica: Yes, yes). I
sometimes think, well I turned 50 last year and I think I've
got to try and sort out what is natural aging and my own
predisposition as well. I have never had kids but sometimes
I'll be out and like if there is a kid screaming I can just feel
like, "ahh just somebody take them away". Then I think,
"I'm overreacting here- just get a grip"- and then I remember
sitting in the doctors waiting room, and everything seemed
amplified, it's like what you said, its like having a bad
hangover but, I am a very moderate drinker you know, I can't
drink more than a glass of wine anyway. It was like I
remember from years and years ago having a real heavy
hangover, my head was throbbing I couldn't take noise my
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wife would put a cup down, and I would just sort of cringe
[holding his head in his hands and everyone laughed]. As a
bloke, I don’t know whether you sympathise with this (looks
at Steven), perhaps its more so than with women, but your
own ego kicks in, you want to get a grip you want to do
something and just get on and do it. But then you feel
defeated. (Steven nods)

I: I am interested…

Steven: I was going to say it’s interesting that you say
(looking at Jessica) that you wear ear plugs at night.

Jessica: Yeah, foam ear plugs, get some, any sort.

Steven: I, I, I do as well because I can’t sleep, I’m finding
that, well the sleep disturbance is part of the syndrome
anyway but another aspect is that external noise has just
become amplified, well any noise just disrupts me
completely. But conversely I have the opposite problem with
speech. So I have to have the television louder in order to be
able to understand it, it’s not the hearing it’s a processing
problem.

Tom: Yeah I found that. (I: Right).
Jessica: I think one thing I found very hard was with understanding people, when I was living with Mike his parents came round once and there were 3 or 4 people talking and I was going like I feel awful now, I feel really ill. Right I don’t mean to be rude but can you go away I need to rest. And for a second, you know the door closed and I (she sighed) and suddenly all my energy levels started slowly building and you could almost feel it. And after about five minutes I felt fine and it was just because I wasn’t being (1) is this making sense to anyone? (Tom: Yes).

Julie: Yes being bombarded with too much at once, you can’t take anything in.

Jessica: It was like my brain was shutting down because it was too much & then it wasn’t too much any more. So I think my energy levels were lower but they weren’t (2) I wasn’t like wanting to shut down and just fall down and crawl under the duvet [laughs] but being under the duvet is quite a nice place to be sometimes but I also, I mean a lot of people I know love the idea of a lie-in. If I am not feeling really knackered I hate lying in bed now. It’s like being put in prison and I used to love that, you know Sunday morning, have an extra lie-in have an extra hour or two, you know
maybe read the paper in bed or a book or- and now it’s just,
(2). Well maybe it’s just me, but that feels like just being in
prison, it’s not the place I want to be. (I: Right). I feel kind
of jealous, not jealous not happy- but you know the joy of
lazing about in bed has been stolen from me [laughs].

I: Because resting has a different meaning?

Jessica: Yeah, well you know I went for a year where if I
managed to walk to the shop literally opposite us and back
again in the day, that was a really exciting day and you know
most of that day was spent in bed. I had maybe five hours a
day awake and I don’t know.

Tom: I tend to be the opposite. My wife could see I was
tired she would say why don’t you go to bed because I was
aching so much I just couldn’t bear to lay in bed. You know
I would rather be up and move a bit

Jessica: I find I vasselate between sometimes I want to do
stuff I haven’t been able to do stuff for ages I want to do
stuff. And then I get to this point where I am terrified to
exercise ‘cause that’s the thing that will make me ill. (Tom:
Yes). And it’s very hard, I mean what you really need to be
is rational about how much you can and can’t do. (Tom:
That’s right). And the thing is it doesn’t stay the same any way, one week you can walk into town okay and the next week you know maybe you can walk to the corner shop, maybe. You know it doesn’t stay the same and your feelings about it don’t stay the same and they don’t stay in line with each other. So some days you should be doing more to be, you know because I, I tend to think you should be doing as much as you can without knackering yourself, otherwise you just go down hill.

Tom: hmm, you just accept this

I: So when you feel that when you physically can do something you do it and when you don’t...

Jessica: No it’s a matter of how much I can physically do is unrelated now to what I feel like I want to do because emotionally, sometimes I am scared of doing stuff, because doing stuff is what makes you ill. Whether that’s a good period or not then other times it’s like I want to do stuff, and you’re like, “well I shouldn’t but I don’t care!”

Julie: Well, the advice I got most often is pacing. You can’t do loads when you feel better and nothing when you feel bad because you will be just be boom and bust it’s about trying to
do a set amount each day. Well I work (2). So it's difficult Monday to Friday to do anything else except work. So when I have weeks where I have to travel to meetings in Croydon and London which means early starts and late getting back I know, whatever the thing they say about pacing, I know I don't want to be doing much that weekend because I am going to be tired. (I: Right). And the upshot was last Saturday I got out of bed at half past five in the afternoon. Because I kept sitting up and thinking, "my headaches and I will just lay here for another ten minutes", and that would be it, I would be gone again for 2 hours. So the pacing actually goes out of the window because there are, I have to do more on some days, it's a reality. It's just the reality of the situation, so some days I do just have to do nothing to make up for it.

Jessica: You have just hit the nail on the head for me. I have got to the point were I keep an energy diary and every day I've divided it into hours, so when I rest it's a plus 1 and when I do stuff that isn't really tiring but it's not resting either it's a zero and when I do anything it's a plus 1. (I: Right). You know, and it has to come to a certain figure. But the problem is that I know, for example, when I am having my period I am more knackered. It's just a fact of my life. That I can manage until the landlord decides to paint the
flat and then I have to move stuff and everything stinks and
then I can’t sleep properly because of the smell next thing I
know I’ve got a relapse on my hands because you can’t
control life. You know shit happens I suppose. I am using
awful language [laughs].

I: How does that fit in to what you were saying Steven about
people with chronic fatigue tend to want to control things so
when it happens, when you develop the illness it’s like a
double whammy really.

Steven: You go into the boom and bust scenario- because
you say to yourself I, I, I’m more than this, you know I can
cope with this, I can recover. But the problem is, you are
back to, you need to be very disciplined in order to say, “No I
shouldn’t be doing these things and/ or I should be very
careful about monitoring the level of activity”. With the way
I do it, is at the moment I am fortunate because I have not got
a huge amount of external pressure- so I don’t have, I am not
working at the moment I am not unable to work- so for me
what I have to do is to say, “Okay I will try and do a minimal
level of activity which will also take me out of the house, to
try”, and, part of the argument is that natural sunlight is
essential for boosting your immune system. (I: Right). And
maintaining activities is essential for keeping your immune
system working as well. So it is incredibly difficult. And
that’s why when you look at other people when you read the
sort of articles that say we’ll tell you how or what you should
be doing, you’ve got to say okay well this is an idealised
scenario but in reality you have got to live your life and you
have got to do the every day things that people have to do.

Tom: With managing it you have to find what works for you
as well because although we have all got a similar syndrome
our personal experience of it would be similar in some ways
but very different in others. You know, I’ve got to a very
pragmatic stage in my life where I’ll do what I know I can
do, sometimes I’ll be at bit cavalier and push the limits but
(2) but I’ve learnt not to do that too much. (I: Right).
Because, if I you know, if I do that then I pay for it, I affect
the household you know, and if I was living on my own it
would be different. So it’s like keeping a balance.

I: So there’s a knock on effect?

Tom: Yeah yeah. I mean my wife works, I’m not working at
the moment. So I’ve taken over all the domestic duties, but
sometimes she’ll come home and I’ve not done much, and I
just say “look don’t worry about it, I just couldn’t manage
much today”. Erm, but I’ve had to do that cause I thought
otherwise, you know; I'll end up doing nothing and
compound the problem. (I: Right). Errr...

I: So there’s something about balance?

Tom: Yeah. I went from like, a very physical job. And
there was still the momentum to be quite physical and I had
to learn, unlearn that if you like. I had to get out that
momentum of thinking. (I: Yes). And that was quite hard
‘cause I know there’s a bit of male pride in there. You know,
I should be able to do this, and then there are, you know,
other pressures as well, financial ones. So like “I’ve got to
get back to work”, but in the end, I had to sit down and think,
“No”. [Laughs] Life is saying slow down, and XXX.

I: So even though you may try and resist listening to what’s
happening to you. You can’t ignore it as you are laid out if
you do.

Tom: Well that’s my personal experience.

Steven: One suspects that one of the reasons you got where
you are, is also the fact that, as a personality type, I would not
listen to my body telling me not to do things, and it’s caught
up with me. You know, over a period of years, I’ve pushed
my, err, stress levels up, you know like adrenal burnout- I think is probably a fair way to describe that, but it doesn’t mean, it doesn’t mean that I haven’t got a physical disease or a physical condition. It just means that my personality and also possibly genetics has predisposed me to getting this.

Jessica: It’s interesting actually, a friend of mine’s got Fibromyalgia, which may or may not be the same thing as ME, but with different things presenting as, more stronger symptoms…

Tom: It’s more joints isn’t it?

Jessica: It’s muscle pain and stuff, but actually her and another friend of mine have both had it, and it’s so similar that it’s beyond belief. But she’s actually studied to be a dancer, and erm, we were both talking that, you know when we were fifteen/sixteen, we were both doing a hell of a lot. I mean, burning the candle at both ends didn’t come into it. I just didn’t need sleep much. Which people never believe about me now. [laughs] But hey! And we both sort of said that have you ever wondered if, because you used to be like this when you were young, you’ve kind of scuppered yourself now? It’s like is it because I overdid it as a kid? (I: Right?) Because I took for granted the fact that I could do so much,
and I did do so much. I don’t know if that’s just feeling like
in someway you’ve got to have a reason that you’re paying
for this now. Or whether it’s a real concern?

I: I understand what you mean.

Julie: No, that’s not occurred to me. I’m very lucky that I’m
still very good friends with the people who were my two best
friends when we were in our late teens and, started night
clubbing, and all the rest of it, four or five nights a week, and
I’m the only one that has this. (I: Right Tom: Yeah). You
know, or anything like it, so that thought actually hadn’t
occurred to me. (Jessica: No?).

Tom: But could that lifestyle, irrespective of your age, erm,
it’s like Steven said, if you’re sort of just ignoring everything,
and just pushing yourself, and that’s a natural way for you to
do things, then nature steps in, it seems you have to reassess
how you’ve lived, whether it stems back to your teens or
later. (Jessica: Yeah). You know, ‘cause if you work hard,
and everything is work, and then there’s deadlines to meet, or
whatever your priorities are, I don’t think, in fact I never have
thought that you can carry on like that, life’s too out of
balance. But it seems that, as I look back, I somehow missed
that message for myself, you know [Tom smiles, Steven
laughs], so I got caught out with it. I mean I know for two
years I worked absolutely flat out. (I: Right). And I did
ignore all the things that I would have told someone in my
place not to ignore. You know like, catching colds a bit more
often, and feeling tired, but ignoring, getting up really early
and not worrying if I didn’t get enough sleep. I can look
back now and say, “Well actually I was doing all of those
things”. And I was setting myself up. (Steven: yeah). So
it’s not so much a mystery, I mean previous to that, life
hadn’t been too demanding.

Jessica: Yeah but theory and practice are different though.
It’s bloody easy to get theory, but getting practice into your
life is different.

Steven: Yeah [laughs]. I think that, just before I forget, I
mean what you’ve said, sort of strikes a chord with me. One
of the things which I think is interesting, is that, that, in all
the time that I’ve being seeing my GP with a variety of
problems that are showing that my body is running into
overload. Erm, so we’re talking about years; so we’re talking
about IBS; we’re talking about fatigue; we’re talking about
upper respiratory infections, all the sorts of indications that
your immune system is struggling. Erm, in no time during all
that, during the time I saw my GP, was it ever suggested that
my lifestyle might be a problem. That actually you’re not
doing your body any good! What you need to consider is, in
general terms is, look at your diet, look at your lifestyle, and
there’s no preventative- I think that’s one of the failings that
we have in terms of our medical services, there’s no emphasis
on preventative care. It’s also treating acute rather than
chronic than chronic conditions, so if you go to your doctor,
and you’ve got an upper respiratory infection, the chances are
he’s going to give you an antibiotic. (I: Mmm). You know
he’s not going to, he’s not, even if they are recurrent, erm,
that’s likely what you’re going to be offered. Rather than
looking at the whole picture and saying, “Well what’s
happening in this person’s life?” Are they (2) well I think
that’s a factor in these chronic conditions becoming
debilitating.

Jessica: Can I ask a question? What advice were people,
when you were first diagnosed, when the doctor first said or
when you said to the doctor I suppose, “There’s something
seriously wrong”, and they said “Well it might be something
along the lines of chronic fatigue”. Did the doctor say
anything to you advice-wise? Or what?

Julie: My GP said erm, “There’s not very much known
about it, because there’s been a lot of studies, none of them
large scale, the Government has just commissioned a large
detail investigation. But the thing that has come out,
the common theme amongst all the small scale projects that
has been done at the moment, is that pacing yourself is the
best thing to do”. And just because there were various
physical symptoms, she was doing the tests one by one to
discount everything else that could cause them. And it was,
“I will refer you to the Chronic Fatigue Service”, and I’m still
waiting for my first assessment with them, nine months on,
so I’m not overly chuffed. (I: Right).

Jessica: Well that’s truthful [laughs with Steven] (Julie:
And err…).

Tom: It was nearer last August mine. No, last June was
mine, well that’s the time it was mentioned.

Julie: July was mine. But she was like, “Come back to see
me regularly and we’ll see what we can do together”. Then I
went home and looked at some websites, and I’m thinking
[gasps] thank god, cause that’s on there and that’s on there,
these are all symptoms of the same thing.

I: Right. So there was something about the name bringing it
together.
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Julie: Well there was part relief at knowing now that there
was this term that covered all these things. (2) But there was
also despair in that I knew I couldn’t get a tablet and take a
course of treatment, and I would be better in a month. And I
knew this could take years, or it could take the rest of my life.
So there was all that uncertainty there ‘cause my GP basically
fessed up straight away “We don’t know what causes it, so
we don’t know how to treat it”.

I: So they were very honest! [All laugh]. Can I just ask shall
I turn these lights off, is it very bright?

Julie: Yes please [investigator walks over to the light switch
and turns it off]

Tom: My doctor said basically the same. She said, “Well
probably it’s chronic fatigue syndrome”, she said, “But
there’s not much I can do about it”. She said, “A lot of it
rests with you and how you adapt to it and how long it lasts”.
And of course I’d been looking at websites anyway, and my
wife’s an assistant manager in a doctor’s practice, so I was
getting a mix of information from her. (I: Right). I think
one of my lowest moments was that a friend of err one of the
staff, a doctor, had ME, and it had lasted seven years. At that
point, I mean this was in the middle of last year, and I was feeling particularly rough and I thought "Oooh", because it was bearing out stuff on the website. You know, they say some people recover within two years fully, some people get about eighty per cent of their health back but it takes up to about five years, and some people don't recover. Erm, it's just there for just years and years and years. And I just thought "oh". [Laughs]. You know.

I: So you've got the uncertainty of one symptom replacing another, and then not knowing how long this is going to go on for...

Tom: Well I stopped thinking in those terms in the end. I thought, I must be more immediate and look after myself daily. And errr (2) don't think about the future, you know. That was my way of psychologically starting to manage it.

I: So when you first found out about the person that had it for seven years that was hard, but then it's changed your management style has changed now?

Tom: Well I suppose part of me didn't want to, well still, three or four months into it I really wasn't convinced it was going to be that bad. I was off work but I was still employed.
And I kind of half-convinced myself, yeah it’s just a matter of time and I’ll be all right. And then Jenny came home and told me about this person who had been, by all accounts much more active in the world than I had, you know, I mean she, but when she said, you know, she’d still got it after seven years and she’s only just started to feel right, I just thought, “Errrr”. You know, and it would be at that point very easy to get disheartened, erm and I did go through a bit of a trough. But I picked up and thought, “Well, I’d have to manage it all myself and not keep looking as to what the future may hold, but just be more immediate”. You know, sort of, again starting to take the advice that I would have at one time said to someone, you know, “Don’t worry about the future deal with how you feel now, and build on that and know what your limits are”.

I: That sounds like it would take a fair time to get around to that point.

Tom: Well I suppose I was lucky ‘cause I was resurrecting old disciplines. You know, years ago I used to be involved in yoga, meditation and stuff. So I had a bit of a background to draw on it, but it was a kind of, when you feel low, you don’t feel like doing it! [Laughs with Steven and Jessica]. I’d go through these inner fights like you know, like, “Am I being
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mentally lazy here? I know better than this!” But some days
I have to sit down and think, “Look you just can’t do it today,
and that’s all there is to it”. (2) But equally the other way, I
knew when I was making excuses for myself, so it’s been a
real kind of learning curve. [4]

I: Right. In response to what Tom has just said, how did
other people feel when they discovered the uncertainty of
recovery?

Steven: [sighs] Well Tom’s right, yeah you’ve got to learn to
filter out the fear- and the negative aspect. Because at the
end of the day you don’t know how soon you are going to get
better, you don’t know if the condition is going to get worse,
erm, it’s demoralising when you talk to people that have had
the condition for a long period of time and their condition
hasn’t improved. Erm, but you’ve just got to learn, it’s really
about stress management, I’m convinced that this is one of
the key factors in controlling this…

Julie: It’s really about accepting that this is your new
reality…

Steven: And you’ve just got to let it wash over you and
you’ve just got to forget your old, you know, it sounds, it’s a
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bit like having to be, it’s a bit erm, the old Steven doesn’t
exist anymore, you know you have to mourn the fact that this
person is no longer here. And it’s somebody else, just as
[laughs] just as irritating or just as nice, depending on which
way you look at it [others laugh]. You’re not exactly the
same person, you know you can’t be the person you were,
you’ve got to learn to become more, well you were talking
about yoga, and it’s about achieving inner calm. And it’s
also spirituality as well. I’ve found that, I have a theory
about the affect that this condition has on the brain. I think
that erm, certainly the people I have met, erm, who have got
this condition tend to be much more interested in spiritual
things than they used to be. Or whether that is just because
you are trying to deal with a difficult problem, or whether it’s
to do with- erm [sighs] the way in which this condition
actually affects your brain. Cause I think it affects my
analytical judgement. I’m a very analytical person. And I’ve
lost some of that. I’m much more intuitive than I used to be.
I erm, I’m also much less concerned about being analytical.
[Back up recording tape loudly stops]. And we’ve reached
the end of the tape; there you go [all laughs]. A good place to
stop.

I: How are you all doing, are you okay? [All participants
expressing different needs e.g. having another drink, going to
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the lavatory, etc]. If we have a break do people want to continue after? [All participants agreed]

Jessica: Yes I feel there are still things that I want to say.

BREAK (Participants helped themselves to drinks and informally chatted to each other)

Tom: It’s made me think about my family history, I know my dad was sort of very uptight, very repressed person. A son, he had from a previous marriage to my mom, was very (2) and it seems to have err brought that out in me. It’s like, after this hit my nervous system is errm you know. It’s like being sensitive to things, you know, like if someone makes a loud noise, I know we all jump now and then but it really gets me on edge more times now than ever used to.

Jessica: But it’s this weird thing that I, I get, I’m like vaguer, but then the phone rings and I’m like “erghhhh!” (Tom: You jump, yeah). And it’s just like...

Tom: It’s a contradiction in terms.

Jessica: Yeah! You shouldn’t be that acute to things that normally make people startle, when you are vague about
everything, it's like well how are you noticing everything.

[Steven sighs]. I just wanted to come back to something
Steven said just before we changed the tapes. About how you
kind of have to start anew it's like, the old me is not in
existence anymore. But when I first got ill for ages it was
like when I get better I will go to university. When I get
better I will do stuff, you know. And there suddenly came a
point, where I don't know what happened but I suddenly
realised that actually you know I, I, I trained in acting and
stuff and I suddenly realised that stage work was something I
was never going to be able to do again. (I: Right). I would
never, I don't know the information at the time wasn't that
you would get 100% better, but a lot of it was like you would
get better, I mean by that I mean maybe 80%. (Tom:
Ermmm). And I just thought well filming for about 12/13
hours doesn't work when you know, being up all hours and
all that sort of stuff, the lifestyle just isn't conducive I will
never be able to do it. I will never be able to do it. And I
went into this deep pit of mourning. (Tom: Ehmm). You
know, having worked all my life, it felt like, towards this
goal, suddenly it was like, "Oh, okay that's not happening".
And it literally was like being in mourning. And at the end of
it, I suddenly started to realise I can't put everything off until
I get better. Don't know when that's going to be? It might
next, you know, it might be six months or it might be in ten
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years. Now I know it might never be And somewhere along
that I suddenly realised actually what I needed to do was to
work out I can live as I am and if I get better it’s gonna be a
bonus I’m not going to be upset about. You know, even if I
only make a 50% improvement then I am going to feel like
I’m ahead whereas before I would have felt like I’ve still got
50% to go. [Julie and Tom agree] You know, so then you
start looking at everything like, “Well I’m better than what I
was”. But the problem is that then you know that most
people are better within five years so I was like for some
reason as soon as that five year anniversary came close [all
members laugh]. I suddenly started being extra careful about
everything I did because I was going to be better in a few
months. (I: Yes). And you know, when I wasn’t I hit that
depression again. And then I came out of it again. And the
same thing happened around the tenth year anniversary,
except this time I thought, “hmmm I’m sure I have been here
before” [laughs]. But, I’m some ways I’m glad in a way that
all those anniversaries have passed. Because I think, if there
was a fifteen-year one that most people are better by, I might
fall into the trap of going, “Yes! This year”, I’m going to
wake up being better and it will work because the odds are in
my favour”. (I: Yeah, yeah). But the trick is, but every time
that hope’s offered to me I go “No, no no- I’m not accepting
it, (gasp), and then I do”. And it’s insane. After the tumour
was taken out, one of my surgeons said “Well you might find
that the ME has gone”. He was horrified that, you know I’d
been ill for like thirteen years and had never had a brain scan.
When a lot of my symptoms were neurological. (I: Mmm).
Which you know is pretty reasonable. And (2) at first I was
thinking, “No, no I’m not believing him”, but everybody I
knew heard the might as an is. She might not have ME
turned into she does not have ME. (I: Right). Because other
people are very keen to see you improve as well and suddenly
my dad said, “Well I never felt quite right about you having
ME. You know I always believed you were ill, but I didn’t
really believe the ME thing, it didn’t feel right”. He managed
to sort of put you know lack of balance and all this together,
to correlate with the part of my brain that was affected- so
that the only thing wrong with me was the tumour. And I
was sat there thinking, “No, no no no no!” the cognitive stuff
that was happening was up here in the front of the brain not at
the back thank you very much. (I: Right). But then…”

I: How did you feel about that, when your dad said that?

Jessica: Well at the time I was a bit like blurb, but to be
honest I was busy buying into the, “Yeah, yeah, I don’t have
ME. I can go and live a proper life, I just have to kind of get
back on my feet from this, you know, this problem”. And
then, to be honest I’d had extra fluids, during the operation,
they chucked me on to an IV and, I have never not felt better
when I have had extra fluids. But I can’t find a doctor to do
that for me [laughs]. You know, if I have a drip I will feel
better for about 6 months. (I: Right). Every time, I had my
appendix out and the doctor, you know you are meant to feel
awful after you have had your appendix taken out and I was
like, “YESSIONS, energy. I can walk into town”. Which for
me was fantastic, and all my friends could see it, and it
literally was, you know, you, you give me a week for being in
hospital and having me insides cut open and stuff, And yeah,
I was a bit bent over and stuff but I had more energy and I
felt better in myself. And every time I have a drip the same
things happened. And there actually research out there,
somebody called Doctor David Bow I think, has found there
is a lowering in the amount of blood actually in your system.
But if you give blood it gives a better result short term but
then if you try it a second time it doesn’t work as well and the
drop will happen again. (I: Erm...) Whereas if you give
fluids, the initial improvement isn’t so good- but it doesn’t
deteriorate in the future, does that make sense?

Julie: I think so, yes.
Jessica: Yes, But I showed some of the research to my GP and he was a bit like “It’s a bit whacky isn’t it?” (Steven laughs) Because when your blood level drops it is meant to change the balance of things in your blood. (I: Right). Well that’s if you cut your wrist or something and you lose it quickly. His theory is that the virus kills it off slowly. I don’t know if this is true or not I just know my experience fits what he says. (Steven: Yes). But there is nowhere I can go to find out more information about it. [Steven exhales loudly], other than sitting and researching it on the web myself. It seems like I keep hearing from different people different bits of research. (Steven: Yep). Some of which sound a bit insane to me frankly and [laughter] other bits fit my personal experience [two group members mutter agreement], and there is no one place you can go where that’s collated. You come across by accident, or because someone said to you, “Oh read something the other day”.

Steven: Can I come, can I comment in on that? Because I really think that is one of the areas where, I think there is a need for service. As a service, there is real problem, in terms of sifting out the wheat from the chaff. Because there is so much information now on the internet..... (Jessica: Mmmm). Some of which is clearly dubious, and some of which is downright misleading. And really what you need is
some intelligent filtering of that information in a digestible form that people can take on board. (Jessica: Yep...) So for example either, erm, an NHS endorsed website, to give advice about the condition, erm, and possibly a Helpline to give people advice over the phone or in any other way they need it as well. And I really do think that as well, because I’ve gone down the same route, I mean it’s interesting that you should talk about, you know, fluids being added, because one of the arguments is that, erm, that the problem with this condition is, erm potassium sodium imbalance in the body. It doesn’t cause the condition, but it’s a possible side effect. (I: Right). And so certain foods might actually help you, so for example, if you eat a lot of bananas, they might actually help you because you are increasing the potassium levels.

Jessica: Yep, yes. I craved bananas when I first got ill...

(Steven: Right...) I thought I was pregnant [laughs]

Steven: It is interesting that careful, carefully digestible advice. (Jessica: Yeah). By somebody that is used to sifting information. And most people, let’s face it, are not used to sifting a lot of information. (I: Absolutely) And also this condition makes it harder for you to sift information.
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Tom: I thought the idea was for you to get that sort of, well,
some information from your doctor, but they’re not
specialists in CFS, but there’s the Specialists we’ve been
referred to at some point, [laughs] you know, we’re waiting
to see, will be able to meet those criteria more. (Jessica: I…)
It just takes so long, I mean… (Steven: Well hopefully!
Then laughs). I said to my doctor when she said well, erm,
“I’ll refer you to this specialist (2) it might be a bit of a wait”.
The last time I saw the doctor she said, “Oh you’ve heard
nothing yet?” and I said, “Well I’m kind of hoping by the
time it comes round I won’t need it”. (I: Right). Cause I got
used to it in my mind that this is going to be a long time and
it’s already been eight or nine months. But going back to the
blood thing. I’ve had no end of blood tests. Erm (3), you
know, I go to the hospital quite regularly. The main thing
they’ve found when I went down with this really heavy virus
before CFS was diagnosed was a low plate blood count. And
erm, the Consultant I saw at the hospital when I said- when
the CFS has been diagnosed- “Would the plate blood count
have anything to do with it?” They were adamant “No”.
And I said, “Well how can you be that sure?” They just said
“No”. I said “Well sometimes when you have given me the
readout which has been as low at ninety at one point so I have
felt genuinely quite tired out but on the higher readings I’ve
not been so bad, so to me there seems to be a correlation”, but
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They’re adamant. (3) (Jessica: Can I be...) They’ve said this
low platelet count is idiosyncratic to me that, you know, I
seem to be living okay. They said, “Oh if it drops to about
sixty or below then we’ll start to worry”. And I said, “Okay”
[laughs] because I am not taking a load of drugs for it.

Jessica: I don’t know, I mean one of the problems is that
what you can’t sift through stuff yourself, but relying on a
doctor to do it is very difficult because the doctors I have
met, some of them have been very sympathetic and some of
them haven’t admitted ME exists. But there’s this general
thing that doctors know, we know, and you’re sat there
thinking well if you don’t know about ME, there’s so much
not known that how can they say when your platelet blood
count isn’t attached- and I keep thinking there’s so many
times where I can see direct links, you know I have fluids, I
have a drip, I feel better always every time. But people keep
saying, “Oh it’s nothing”, and maybe somewhere it would be
nice for researcher got in contact with everyone with an ME
diagnosis and says well what has worked? (Tom: Erm).

You know, to you. (Steven: Yes). Nobody has done this!
The other thing is there are several things out there that are
possible treatments, you know, B12 injections (2) I don’t
know if anyone has heard of those? (Julie: Well, I had...) I
heard about them when I first got...
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I had a low platelet count as well, which was put one of the possible causes of this is low B12. But when they tested my B12 level it was fine. (Tom: It was fine yeah). (Jessica: Yep).

Did you recognise as Tom did that you felt better when your platelet count was higher?

I basically feel crap all the time.

My blood platelet level was low as well but that, but that was in the early, that was in the very early stage, sort of like first flare-up of the condition.

Yes, this was all to do with the diagnosis. (Steven: My, my blood...) I applied to a new dentist recently, and you had to list all the inoculations and blood tests you had had since you were a child. And they gave you a box that big (gestures a small amount between thumb and index finger). [Laughter]. Now I like to travel, my inoculations nearly fill that. [She laughs]

But what I was going to say was in the whole, there are some treatments out there that some people think might
work or might help is, you know, I heard about B12 when I first got ill back in, what 1991. The second GP I saw, 'cause I had to, I moved, erm basically said, “Well there is not a lot we can do for you and I feel really awful, I know you are suffering but I don’t know of anything that works”. And I am like, “Look this has reasonable basis can you look into it”, and basically unless somebody gave you a cast iron guarantee that it would work and that it was, is it licensed? (I: Right, yes). That actually when the NHS says yes you may do this with this condition. Yes, they won’t do it. [Steven sighs]. But the problem is, that if nobody tries it how will it ever get licensed? (Julie: Mmmm). So there’s lots of these possible treatments out there, but no GP, you know, GPs are very reluctant to try things that aren’t licensed because it’s on their head on the block... (Steven: Mmm). And you’ve kind of got this catch twenty-two...

Steven: Yeah but you’re also into snake oil aren’t you! Into the whole business of saying well you’re trying to, you know, when people get desperate they’ll try almost anything.

(Julie: Yes). And you know there’s a point where, where, where it just starts to be counterproductive to try anything and everything. And I think we are back to what’s needed is some, a good research into, into causes. (Julie: Mmmm).

First of all finding out what the hell is going on in people’s
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bodies. (I: Yeah). The real problem I suspect, there certainly
seems to be good evidence of this is that we are not dealing
with one condition. We’re not, we’re not dealing, the
symptoms are, err, can, err, of chronic fatigue syndrome can
be, err, is likely there is more than one medical condition
which takes you to this end point which is called Chronic
Fatigue Syndrome. Which is why some treatments seem to
work well for some people- something and other things don’t.
I mean for example, the antidepressant Sertraline seems to
work well for some people with ME. Other people it does
nothing for. And likewise, some people say, for pain for joint
pain, magnesium or muscle pain, magnesium supplements
have helped an awful lot; they do nothing for me. So it’s a
real, you’re on to a hiding into nothing, so I can understand
the reluctance of a GP to try you on the latest… (Jessica:
Oh yeah). The latest fad, for want of a better word. (Jessica:
Absolutely).

I: I can understand both of your perspectives. I went to do a
lit review last week and there were eight thousand things on
one database. I found it quite confusing, and some
information is so complicated, you think what does this
mean? I can see the point that says, try it go for it, but also I
can see that when does it end?
Jessica: I don’t believe in trying everything. (Steven: No no no). Please don’t ever think that…

Steven: But the real problem is there are people out there, who- for want of a better word- exploit other people’s weaknesses… (Jessica: Oh absolutely…) And the trouble with chronic conditions is that they are open to that kind of manipulation. And also with the best will in the world, your friends come up with things, have you tried this have you tried that? And you get to the point where you look at these things and you think to yourself, “well this must be a load of old bollocks”. (I: Yes) Excuse me for saying that [laughs], because some of these, some of these therapies are clearly of a fringe nature. And the difficulty is getting a balance between having an open mind, a reasonable open mind, to say well actually this could work for medically sound reasons. This possibly could work compared with those treatments which you say well current levels of knowledge, this is a total waste of time.

Tom: If we’re talking about treatments, I haven’t mentioned up until now because I get sick of people’s reactions. I’ve got a friend who is a doctor down south, who is also a homeopath, I mean he teaches homeopathy not just in this country but abroad, but he is a medical doctor. And I went to
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see him, as I was thinking this just can’t go on you know so

and he has tried me on different remedies but one I took in

November I really thought we’d cracked it because within a

few weeks of taking it I felt like I used to feel. (I: Yes).

And that lasted for about nearly two weeks … and then it

wore off and it’s never been, I mean it’s got him frustrated

because…. (2) everything else he has given me. He has

explained it to me- and I know about homeopathy – “I am

trying to find a culture that fits the picture you are presenting

me, and he said there are remedies that obviously are very,

present a very different picture but you get, like colours in a

rainbow so are side by side, and the subtlety of difference

between them, it’s sometimes very hard to find a remedy

exact”. So he said, “In a way it’s trial and error”. I said,

“Fine I’d rather do it with a homeopathic remedy that can’t

hurt you than be experimenting with drugs”. (I: Yeah sure)

Erm, but it did make a, you know I really thought this

November, we’ve done it! And I mean physically all my

strength was back but- after two weeks I dropped down, but

to be fair I’m better than I was last year, but I found the

winter very hard. I got very sensitive to cold, my strength

goes if I go out for a walk and it’s cold. (I: Mmmmm).

Jessica: Yeah no one told me about seasonal variation.

(Steven: Mmmmm).
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Tom: Yeah my doctor actually said in December, "You know if we have a hard winter you might find this is hard going". And, you know most of us live in fairly warm houses and that these days, but if it's cold outside it's bizarre how it affects me. (I: Right)

Julie: Very much what going through with my GP is we are not trying to treat CFS at all. (Steven: Yes). She has admitted that she's just not qualified, I don't expect her to be she's a GP she's not a specialist. It's about learning to manage the condition. (Tom: Yes). And what she treats are the symptoms. I've got, I ache, I hunch up, I work with a computer. All this creates bad posture; which creates bad headaches. She suggested that I get acupuncture for that. (I: Right). At my request finally for some painkillers, 'cause I can't always get out to the acupuncturist I like very easy. So just some painkillers that will help me make it through. Because it's a very particular type of headache it's like something's been hammered from the back of my head to the front [she gesticulated the movement of pain with her hands]. (I: Right). Mmm, she has suggested that I try yoga or the Alexander Technique, which is to get some gentle stretching and exercise, and things like that. And that's what we're
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1222 doing, it’s about managing it… (Tom: Yeah). And that’s
1223 what we’re doing, it’s about managing it…
1224
1225 Steven: I think that’s the best we can hope for, because in
1226 the absence of good evidence-based medicine about what this
1227 condition is about, then you are stuck. So you, you have to, I
1228 mean I, I was thinking about ideas in terms of service
1229 delivery. Which is presumably what you are really interested
1230 in? And I think all of the things we have been talking about
1231 fit into that. (I: Mmmm, they do yeah). I mean, pain, pain
1232 management clearly is something which would be of
1233 particular use to some people. Meditation, yoga, relaxation
1234 techniques, stress management, all of these sorts of things.
1235 All of the areas we haven’t talked about really yet, which I
1236 think actually is quite a significant area, is dietary
1237 management and nutrition. (Tom: yeah) I really do think
1238 that…
1239
1240 Julie: When somebody said to me when they knew what I’d
1241 got that they had an ex-girlfriend who had ME, and it’s “Oh
1242 you have to completely change your diet don’t you? She had
1243 to cut out this and that and the other”. Well the research I’ve
1244 read shows that for some people it helps and some people it
1245 doesn’t. My struggle is to eat! (Steven: Right). I can’t be
1246 looking- you know I live alone- and I’ve got to the stage
where every now and again, you know, my boyfriend, he did
it twice last week, turned up at my doorstep with a box full of
stuff and he cooks, because he knows left to my own devices,
I won’t eat, or I might eat a dish of Cornflakes.  (Steven:
Right) Because my appetite has dropped and I don’t have the
energy to prepare a meal.  (Steven:  Yeah).  So I can’t be
looking at adjusting my diet...

Steven:  No, but well, that’s interesting because you can
argue that you do need, you are exactly in need of good
dietary advice, in terms of the kinds of foods… (Julie:
Well…) which are palatable to you...

Julie:  But it’s got to be easy to prepare...

Steven:  Exactly, and also presumably one of the risks for a
person in your particular situation, is that you may, you might
be actually moving towards eating much more junk foods...

Julie:  I do I live on cornflakes and frozen foods…

Steven:  Foods that are low in nutrition…

Tom:  That might exacerbate your condition….
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1272 Steven: Which actually could make it worse! The one thing
1273 which has, has helped me, which I was surprised about
1274 because I didn’t really think my diet was that unhealthy, was
1275 by almost totally excluding sugars in my diet. I found that
1276 the symptoms have been alleviated significantly, the physical
1277 side.

1278

1279 Jessica: Yeah. It helps, I have to admit when I first got ill,
1280 Coca Cola, cause hey sugar and caffeine good mix when
1281 you’re struggling [Steven laughs], and chocolate…

1282

1283 Julie: Mine was Lucozade till the tartrazine brought me out
1284 in a skin rash.

1285

1286 Steven: Yes yes [everyone laughs]

1287

1288 Jessica: But Unfortunately they do make it worse. But the
1289 problem for me is on the one hand, yeah a dietary advice
1290 really useful, but on the other hand I mean I don’t know what
1291 your situation is but I’m single, I live on income support with
1292 disability premium. I have forty pounds a week, to spend on
1293 everything excluding bills. (I: Right). (Steven: Right).

1294 Everything. Now I have to feed my cat, I have to feed me. I
1295 have to get from A to B, and I can’t drive. It’s like yes you
1296 can give me dietary advice until the cows come home but I
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can’t afford to buy lots of fresh food, I can’t afford organic
stuff, I’d love to because I’m pretty sure that chemicals don’t
help. But how do you do that?

Steven: But, but we’re back to needing realistic advice
aren’t we. Because I think, because (2) somebody in your
position, I mean an immediate response, I would so, well
okay you haven’t got a lot of money. So what you need to be
doing is looking at cheap, you know, cheap nutrition. So for
example, increasing the portion of fresh vegetables in your
diet for example. Erm, eating more pulses, you know, all I’m
saying, you is that it has to be tailored to the needs and the
requirements of the individual...

Julie: It is a holistic thing isn’t it. (Steven: That’s right).

Julie: It needs a range of things. Now at the minute I’m
being advised to try acupuncture try yoga, but I’m having to
go out and find that for myself. (Steven: Yes).

Jessica: And again it comes back to the money thing. I
know yoga works, I know acupuncture will help me. I know
Chinese medicine will help me. Even though I was having
continuous improvement with the Chinese Doctor, and he
was going out of his way to, when I was saying that my
money is running out, this is really helping, sometimes you
can really tell that it’s the best treatment I’ve ever had. (I:
Mmmm). And he was saying, well okay, instead of having
this brand, we can treat, we can cut it down to this brand. I
won’t charge you for the acupuncture, just for the drug, you
know the herbs. (Steven: Mmmm). Erm, so he was giving
me consultations for almost half price. But that’s all well and
good, but (2) still I couldn’t afford it for very long. (Steven:
Sure). And it’s gutting when you know something’s
working. I got no help to get this again. But then there is...
(Steven: Yeah). And it’s just like (3) I don’t (2) I don’t have
the words for it, sorry.

Steven: Yeah, I mean it’s horrible, but then you can also see
it from the point of view of the service provider, you know,
the health service, because the bottom line is that there is a
limited amount of money to spend on healthcare. So
therefore you have opportunity, therefore you have to, you
have to spend that money on that which is proven. Or you
believe is proven to have advantage. (Jessica: Yeah). And
if something is unproven to have advantage in our society,
like Chinese medicine, you can see that, that money isn’t
going to be there to do it. (Jessica: No but…) Which is
heartbreaking for you as an individual because you know
you’re- you’re the one who’s caught up in that.
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Jessica: Absolutely but I mean, I mean the management thing we’ve kind of talked about, but the reason why I asked what advice you had been given by your doctor, was, I was given eat well rest well. Well that sounds like, when you’re pregnant, put your feet up in front [laughs] of the telly, and try not to eat junk food. Yeah. I now know that if I manage things, you know, and the stricter I am the better it works. But I know I can’t stick to that every time. You know, there will be times when people are like, “do you want to go down to the pub”, and I’m like I have to be going to sleep by ten, sod it, I would like a social life as well. So every once in a while... (Tom: But...) I break it and I feel crap...

Tom: Sure, but that’s quite healthy I think.

Jessica: Yeah. But nobody told me about this management early on. And I honestly believe that the earlier you try it, the more likely you are to have good improvement. You know if you need convalescence, you need it when you are recovering from the illness, not six months or a year later...

I: So bearing in mind...

Jessica: Does that make sense?
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I: Yes it does. I'm just curious that your symptoms started in 91', so over this time you've had lots of different advice. I mean, I know that both of you [directed at Julie and Tom] have said that your GPs have told you that they didn't know much about it but they would try and help.

Tom: Well I saw my own doctor and two doctors from [Company Name] that I was working with, and then a doctor from the Incapacity Benefit people, and they were all pretty supportive. They didn't disbelieve me, I mean they could spot most times that I was pretty exhausted...

Jessica: Someone from Incapacity was believing of you!

[Demonstrated a shocked expression].

Tom: Yeah, he was fine. I mean I went there expecting an ordeal... (Steven: MM.). Because I knew, particularly with Government Legislation, but he asked me loads of questions, basically which was a repeat of the form I'd sent to in, and he did some tests on me, and I said, "What happens now?" And he said "Well I just submit this, all scored, and if you fall within the right scoring bracket you will get the benefit and you don't, then it's up to, you can either challenge it, you'll be..." (Jessica: What...) "Be seen by another doctor". But
it was about five days later, so my personal experience of that has been okay. But I know some people don’t have that.

(Steven: Yeah [sighs]). But in terms of very practical advice, I mean when you are seeing a doctor it is general, because they are general practitioners. They do advise you, just look at your diet, look at the way you live your life. You have to have personal responsibility and take on the detail of that… (Jessica: Yeah but…) I know when you’re feeling bad, well for me it’s been a case of (2) I hadn’t wanted to do it, but when I’d gotten through the worse of that particular phase, I’ve then taken it up.

Steven: Yeah but then were back to this issue, that the bottom line, there is no, as far as I have been able to determine, there is no credible one source of information that you can get help here. And really, this is the kind of service that ought to be provided by…

Tom: Isn’t this, isn’t this the specialist service that we are going to see?

Steven: Well that’s right! But you need general access to it. I mean what you’ve said is actually damning for the service that is being provided here in Leicester. The reason that I say this is because, I think that it is unacceptable for erm,
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individuals who have been diagnosed with this condition not
to be given access to information by a service which is
purporting to help them. Now you were talking about, what
nine months did you say that you’ve been so far on the
waiting list? [Nods]...

Julie: The only letter I have had from them was to introduce
you, they have never even acknowledged that they have
received the referral. (Steven: Right...)

Jessica: I only got an acknowledgement because I phoned
up to say excuse me...

Julie: My doctor’s had a...

Jessica: How long is the waiting list.

Julie: My doctor’s had an acknowledgement, which she’s
told me about. But I received that one letter...

Steven: So clearly there is an issue that the service is clearly
clogged up in terms of the resources that it has got, in terms
of the individuals it can see. But there is an issue, and okay,
but there is an issue about what you do with people in the
mean time. I can’t understand why it’s not feasible to
generate information packs, a good website presence, and
basically to write to anybody who has been referred to say,
you know, “You’re on the waiting list to see us, in the
meantime that we have a helpline, we have this we have that,
which will hopefully give you a bit of advice that will be
useful while you…”

Jessica: Absolutely. The other thing that you ought to be
told is an estimate of how long the waiting list is.

Tom: Yeah, you know, that’s true, as… (Jessica: Even
if…)

Tom: You got no feedback whatsoever…

Jessica: Even if you are told, like, nine to twelve months.
You’d be like “Oh bloody hell that’s a long time!”

Julie: But you’d know wouldn’t you…

Jessica: But the thing is that you wouldn’t be spending the
first nine months going, “where’s my letter, where’s my
letter?”
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1471 Steven: Well you’ll probably find that the waiting list is
1472 probably measured in years. Erm, it would be interesting to
1473 find out what the waiting lists are for this service. (Julie: 
1474 Yeah).
1475
1476 Steven: Erm I mean I know, cause erm…
1477
1478 Julie: The letter to my doctor just said “due to a lack of
1479 funding and lack of other resources, we have a waiting list of
1480 several months”. (Steven: Yeah; Jessica: Yeah).
1481
1482 Steven: Yeah I mean I was on a waiting list for cognitive-
1483 behavioural therapy, and that was, took nearly three years.
1484
1485 Julie: My problem is, you know, meanwhile I’m holding 
1486 down a full-time job.
1487
1488 Jessica: I don’t know how you are doing that…
1489
1490 Julie: Now…
1491
1492 Jessica: I’m sorry
1493
1494 Julie: Now my employers, I work for a Human Rights 
1495 Charity, so they are a very caring employer. They have
allowed me to work from home in the morning, which
helps... (Steven: That’s right). I work from home all day a
lot, some of the time. And when I get bad, my doctor signs
me off for two weeks with exhaustion. (Jessica: Yes). And
I’m not quibbled about the amount of sick leave I’m taking.
(Jessica and Steven: Right). However, I finished a major
piece of work in the middle of last year. So my workload has
been somewhat less than full since then. And now, they are
starting to say “well your work load’s not, and [Steven
laughs] it’s come to I’ve got to look at reducing my hours.
(Steven: Erm). And I can’t get, you know I’ve gone to my
GP before and said “This is wrong and that’s wrong, and I
don’t know how to manage this”, and she’s said, “What do
you want me to do?” (2)

I: What is that like to hear?

Julie: Well it’s devastating, but equally I’m realistic enough
to know she is only human, she’s a GP.

I: And she’s been honest with you.

Julie: She is very honest, I have the utmost respect for her.
Erm, but it’s like, “You’re my only port of call. If you can’t
advise me, who do I talk to, 'cause I don't feel capable of
making this decision on my own". (I: Right)

Steven: So we’re back to, sorry, we’re back to having a
professional advisory. (Julie: Yeah). I mean I was, sort of
thing was, well one of the things that struck me as being
ludicrous was that I was looking at the whole issue of benefit
because I’m not able to work at the moment. And the whole
process of whether I could get, I mean the Incapacity Benefit
was not particularly difficult for me to get, but the whole
issue of whether I might be eligible for Disabled Living
Allowance for example, there was nobody, the only place I
could go to for advice was the Citizen’s Advice Bureau. And
I thought really this isn’t really on.

Julie: And we don’t even have that in [name of City]
anymore.

Jessica: No. And also it varies, I mean at one point I hadn’t
heard of it for years. Then I heard about it I applied and I got
erm, I was struggling to walk anywhere, but all I got was the
ten pounds extra a week cause I couldn’t cook a meal for
myself. Then when that part finished, yeah, they said that I
didn’t need any help at all. And there is no balance, and the
problem is that the forms don’t apply to ME. Do you need
help? How many days a week? It's like, well some days, I need it lots; I have good weeks I have bad weeks. (Steven:
Yeah [sighs]). And you're told you can't lie on the forms but if you phone up for help, they say, “Well if you average it out over the year how does it work out?” And the thing is, well I don't know, maybe I'm being silly, but there's this paranoid thing where you've said something on the forms. (Steven: Mmmm). And you know it's not a hundred per cent true, but then if you stretch it over the year it is, yeah, but then if somebody filmed you for a week, a good week, they'd go “You're lying your head off”. (Steven: Yeah). So it's like, what am I supposed to do? (Steven: Yeah but...) And there is a big problem to me between, 'cause actually you need help from the benefits people and the doctors, and never the twain meet. They don't speak the same language, they don't communicate. And I'm at this point now that if I manage everything I can feel okay. Yeah. And I'm thinking I want to start working, but to do the job that I want to do, which is the only way I could work, sort of ten hours a week, which I can manage and pay my way, is to do a one day a week course for two years. But if I do that I might be proving myself fit to work. And there's this whole catch twenty-two. (I: Yeah yes). Where to keep myself well, you know, if you break the rules for keeping yourself well you'll end up for qualifying for higher levels on the DLA stuff. But if you
follow the rules, you don’t even qualify for anything at all.

And so, what kind of situation is that, it doesn’t fit anywhere.

There is no help for you to, to actually work steadily towards work. My GP would love to help me. He’s actually sat there and said “Your plan is excellent, you are being very sensible, but I don’t know how you are going to make it work with benefits”.

Tom: This is, well that’s all up for grabs anyway, isn’t it!

Cause perhaps after the election it’s all going to change.

(Steven: Yes).

Jessica: I mean my friend’s got another problem, you know, she’s just applied for Incapacity at the same time they are trying to cut down on people committing fraud... (Tom:

Sure, yeah). And she’s been told that she’s got to keep working by her family, and I can see she’s really not up to it. You know, she drags herself into work, is twice as ill the next couple of days, em...

Steven: You know, I think you are raising some very broad issues about the whole...

Tom: Yeah the politics of it
Steven: The whole issue of the benefit system not being optimised to assist people in getting back to work. Cause as you rightly say. The other problem that relates to that is that there is a danger that it actually discourages people from getting better as well. (Jessica: Mmmm). Because it if you are financially penalised from trying to do a certain amount, then you are not going to try to do it. There’s no incentive for people to try and work part-time if they know that their benefit is going to be taken away. And with a condition like this, where the condition that is so variable, you have got no safety net. Because if you go back to work and find a week later, a month later that you are back to square one, then you are into the whole rigmarole of having to claim benefit afresh, and so on and so forth.

I: I suppose, going back to your point earlier Jessica that may be compounded by the fear of doing something that may make you ill.

Jessica: And the thing is, it is a real physical illness with psychological consequences, and it’s one thing I was going to try and bring it back to anyway. I think the service needs to be not just about learning to manage and stuff, but also there’s a psychological component that goes with being ill for a long time. (I: Yes). It gets you down. It’s people not
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believing you, and I would love to be in a situation where
once every so often, there is somewhere I could go, and I can
just go “Blurrrr” [gestures verbally pouring out]. (Tom:
Yeah). Here’s some of my madness. Here’s my frustration.
here’s my grief, just have it [laughs].

Tom: Yeah yeah, that kind of support would be a great
resource.

Jessica: And it’s also something, I mean, when I was living
in [place name] there’s a charity there called [name of
charity], and they provide a counselling for people with ME,
and the counsellors know about ME. So instead of having a
complete non-interference thing going, they’ll actually say to
you, “I’m really glad you’re feeling better but do you think
you’re being realistic about the amount you want to do?”
And that is a really hard thing to hear, but you need
somebody to say it. Because every time I feel better, I
always want to do too much, it’s just your natural drive is to
do what you can.

Steven: Can I ask a question about, I mean one of the areas I
wanted to just ask about was, erm, the whole issue of self
help groups and experiences of self help groups. (I: Yes).
Because it struck me that one of the areas where assistance
could be provided is in actually providing assistance for, you
know, such groups to be put together, and to also help them
in their activities. I mean I'm, I'm loosely involved with a
group, a [name of city] support group called [name of support
group]. And that was really by chance, by me sort of looking
on the internet and trying to find, well you know, thinking
should I get involved with this sort of group or not. (I:
Right). And it struck me that these are people who are trying
their best to help other people, and they're struggling
themselves, and it would have been incredibly easy for, you
know, a service to provide some administrative support to set
up a website to help people get in touch with other people.
But that side of it just doesn't seem to be part of the service
delivery mechanism.

Jessica: In some ways I think that is a really good idea but in
other ways I have to say, my experience with [name of
charity] was incredibly positive. My experience with some
other groups has been, erm, "Oh yes, I'm really ill" [makes
muttering noise of someone talking]". And it's all about this
person, and then they're telling me they found out about this
research project, and this one and this one. And you come
round to the point of, well how did you find out about that,
and suddenly they clam up, because there are limited places
on any research project and they don't want to spoil their
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chances of getting onto it by telling you. And I just felt like I was just getting this, “I’m iller than you”. And I don’t want any of that crap. I know that sometimes I’ve been much iller than I am and I’ve been much better than I am. (I: Mmmm). And I don’t want to get into a “I’m iller than you are, I’ve had it for two months more than you”. I don’t give a toss!

I: Well I think that that can happen...

Jessica: but....

I: That is really up to the group members to manage that dynamic.

Jessica: There are people that haven’t.... (Tom: Yeah). There are other people that haven’t been ill for such a long time that have been much iller than me. Or they have had more supportive or less supportive families. Your experience isn’t just to do with how long or how bad.

Steven: Yeah. The good advice that I’ve received in terms of dealing with this condition has been either been a combination of either me looking on, you know, trying to gather information and read books on the internet. But also, I have to say, from talking to other people, who have said
“Well look, I have had this problem and I found this helps me, have you tried this, have you tried that”. I think you’re right, there is a danger, I mean, it’s a balancing act because there is a danger as well that you, I mean nobody wants to spend all of their time talking to people who are sick. Let’s be honest, I have no desire to spend all my life talking to other people with ME. (I: Yes).

Steven: But I do think there is a place, if it is carefully managed, for advice to be.... (Tom: Yeah). And also support as well ‘cause we know there aren’t resources to provide the support you actually need. I go to my GP maybe once a month. Fifteen minutes is maximum time that, that, for an appointment with that person. That is, for somebody, you know I can’t do a brain dump in fifteen minutes with the problems that I am having [all members laugh]. (Tom: Certainly). You know, he only wants to hear one fart [laughter continues]. He says, “That’s it, I’ve had enough! I can’t help you with it all”. And you need, you need...

I: Do you think there is something about the professional feeling that they cannot help you, so that creates a feeling of uselessness in them, that may be pushed back onto you?

Tom and Jessica: Yes...
Steven: Absolutely...

Julie: Yes it frays their expectations...

Steven: We're back to chronic conditions being incredibly difficult to treat. And your doctor wants to have an acute condition because it's easy to treat an acute condition.

(Jessica: Mmm Mmmm). You know, this person has got X and we'll give them Y, and they will get better or we'll try another treatment. Whereas with something like ME, I mean you're into a hike into nothing, and it's depressing for the doctor. You know, you know there's jokes about what appears in people's medical records, you know like "God only knows" you know, things like that. Because there is a hardcore of patients who keep coming back with chronic conditions which the GPs can't do anything about. (I: Sure).

And unfortunately we fit into that category as well.

Jessica: I've got a slight problem with hearing resources all the time.

Tom: But it's true though isn't it!

Jessica: It's nothing personal.
Tom: No, it's a fact of life.

Jessica: It is, but no, my problem is that ME is not, I suppose I keep saying, sexy illness, you know, it's not very exciting, it's not media-worthy particularly or anything. But there are a hell of a lot of people out there with it, and the resources provided for us do not in anyway connect with the amount of people with ME, you know. There are, I think, four or five centres that deal with ME, and by that what we're talking about is clinics like the one in [name of city] yeah, in the country. (Tom: Mmmm). Yeah. Now I know as many people, [one tape goes stops loudly], one of them is recording isn't it? (I: Yes). I know as many people with ME, probably more than I know who have had cancer. Yeah... [Julie sighs]. (Steven: Yeaaaah).

Jessica: Now I know cancer kills you...

Julie: Yes this is a point. There are people dying for the lack of intensive care beds. (Jessica: Yes)

Julie: And that's got to be more of an immediate priority...
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4 Participants from Waiting List for the CFS Service

Steven: Yes, and also, also it is impossible for, as an
individual to see a broader picture, because our own
experiences draws us to people with similar, we become, our
experience is based on the contacts we have and the circles
we move in. So, so, it needs to be based on acuteness and
also on demographics, in terms of most common diseases,
and debilitating diseases and so on. But having said that, I
think you are absolutely right, not enough has been done
about this condition, because there is still the attitude, and
I'm fortunate because I've not experienced it directly, but I'm
told by a variety of people that have had this condition for a
longer period of time than me, that there is still that attitude
that, you know, this is not a real condition, this is, you know,
a psychological problem… (Jessica: Yeah). You know, all
we need to do is, is give the person some cognitive
behavioural therapy, give them some graded exercise, and the
problem is going to go away.

Jessica: Mmmm. I would like to actually have a list, I mean,
every county to have a list of doctors who believe in ME.

Because when I moved from [name of city] to [name of city]
I phoned round all my local surgeries and I actually had a
situation where, I phoned up the receptionist to say, "How
does your doctor feel about this?" And one of the doctors
grabbed the phone off his receptionist and said, "No, no no
ME is not real, what you have is depression and I can treat that and I can make you better’. My response was ‘Thank you but no thank you’. [General laughter from participants].

(S Steven: Next!). I’m really not interested, and he tried to keep me talking. But the thing is right, have you tried finding a doctor who believes you, No — I mean, it’s really difficult!

And because of things like the Data Protection Act people keep saying, “Well we can’t keep lists like this”. So you end up finding people with ME and going “So what doctors have you heard good reports about?” (Tom: Absolutely). You have to go by word of mouth and then it’s really down to potluck. And with me you know, I’m now at the second surgery in [name of city] after having done my phone round and it’s marvellous, it’s one of the best doctor’s surgeries I have ever been to and the thing is I don’t now want to move. (I: Right). You know it’s insane to base where you live by the doctor you’ve got. But the reality is that if you have a chronic condition, your GP is actually a very important factor in your life.

I: Can I just draw your attention to the time. How is everyone? [Laughter]. I have found this is very interesting, and I am thankful to gain this insight. Is there anything that anyone would like to say briefly, if you feel like you have not had the opportunity to say it so far?
Jessica: Yes I would like to say that when you go into hospital, you are usually placed in wards with old people that moan or outright chat when you are trying to rest. This is not a good place to be when you have this condition. You come out feeling worse!

Julie: Yes but that is probably most people's experience with a range of different conditions.

I: How have you found the discussion today?

Tom: Yeah, useful

Jessica: I could just talk and talk about it

Steven: Yeah

Julie: It's been okay, I wouldn't like to do it too often. But if there is anything you need to clarify I don't mind you contacting me.

Tom: Yes

Steven: Yes of course
I: Well thank you for participating in the group.

Tom and Steven completed their mileage forms and handed them back to the researcher. Julie stated that she had forgot to clock her mileage, and so would send it to me at a later date. Jessica needed to ascertain a receipt from the Taxi Company for her return journey to send back to the university. Participants and the researcher talked generally amongst each other. The focus group was two hours in duration.
Focus Group 2: 14th March 2005 at 2.00pm.
Venue: Activity Room at the Cedars Centre, 5 Participants

1. I: There are a number of things we need to go through before we start the discussion, okay. The first thing is that basically I am looking at people's relationships with the health service, and more specially the [name of city] Chronic Fatigue Service. Now everyone here is currently having treatment? (Group agreement).

2. Basically what is going to happen with the results is probably more towards the middle or end of this year I will be handing my research in. I will be looking to publish the results—hopefully in a journal that the medical professionals may access. I will also produce a report to go to the Chronic Fatigue Service and a report will be sent to you. Is that okay? (Group agreement).

3. I was thinking about doing a presentation for all parties to attend. I guess I could still do that- but I understand that not everyone is going to be able to make the date etc., so a report would give you some means of getting the results.

4. Right, confidentiality I have already touched on that I am not going to use anyone’s name, professionals we talk about today their names will be taken out and place names will be taken out.

5. So ground rules - really if I may propose the first one is that basically what we discuss today stays in the room today. [Participants show agreement] Has anyone else got any suggestions that they would like to make, like what would
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make them feel more comfortable? (4) No, right okay. So it is ten to three now. How do you want to do this? Shall we talk for half an hour and then have a five-minute break and then go for another half an hour?

Pat: Don't mind!

Fiona: It's nice to have a middle break

[Others indicate no preference].

I: Yes okay so shall we say at twenty past three we will stop for 5 minutes?

Rose: I will have to leave at four o'clock and no later because I have got to get to work.

I: Is four pushing it or is that okay?

Rose: Yes but as long as it is on four I can manage it.

I: Okay well thanks for saying that. [Turns to assistant researcher] and can you keep an eye on the time? (II: Yes). Also there is another form that I wanted to give you, basically what this is - a lot of it I already know from talking to you on the telephone, but it is basically some information about you.
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51 I’ll give you some envelopes and for you to send it back in
52 your time really. If there is anything you are uncomfortable
53 with and you don’t want to answer – don’t that’s fine.
54 So if we may start. The first thing I want to put to you to
55 think about is that you are all currently having treatment – so
56 how is it going? What have you made of it so far?
57
58 \textbf{Pat:} Me – I don’t know what I would do without it. (I:
59 Right). I mean when I first got it, I’ve had it nearly 2 years
60 now, and I mean \textbf{I couldn’t even get out of bed} and all the
61 help I’ve had from [name of hospital] with [name of
62 therapist] she has got me to organise my life all over again
63 and she really helped me, really helped me. (I: Right). My
64 doctor has been lovely. She has been smashing; I mean it
65 was her that sent me there. I’ve had an understanding doctor,
66 an understanding receptionist – they have gone out of their
67 way to help me. (2) Erm, (1) they’ve sent me leaflets in the
68 post where I can get information from. I have been to the
69 library, and they’ve have got books for me, they have even
70 ordered books for me to read all about it. (I: Right) And
71 when I’d read these books I realised I weren’t going mad
72 because I thought I was \textbf{going mad, I honestly did}. And
73 when I read those books I thought well \textbf{that could be me} –
74 what I was reading – \textbf{that could be me!} And that made me
75 feel better to start off with. And erm, (2) it’s not been \textbf{easy}. 

80
Sometimes you know, as I say you don’t believe, believe half the things like, you think I shan’t, I will never be able to do that and I will never be able to do this but… (I: right). But whenever I’ve got doubts [name of therapist] gives me – she explains it to me and gives me another way to do a thing, which I do and see how I improve. (I: Right okay). So I can’t fault the help I’ve had at all. I know people who have had no help whatsoever! Friends who have had no help whatsoever. (2) I mean one friend I know that has had this before me she manages to go work one day a week now. But I mean she has no help, no help whatsoever. I’ve had, I mean I’ve been lucky I think with the help I’ve had.

I: So she’s managed to get back to work.

Pat: Just one day a week. She used to work full-time – by herself yes. But erm, (3) you know she has had no help – it’s been really hard for her – she’s had it for about four years!

I: Right – so you’ve had a positive experience in terms of getting support.

Pat: Oh yeah, yes. If I hadn’t- I mean some people don’t believe in it. And I know a lot people who don’t believe in it and there are a lot of doctors don’t believe in it. And if I’d
have gone to somebody like that, well I don’t think I’d – well
I most probably would done away with myself before now
[laughs]

I: Right- you said, you thought you were going mad?

Pat: Yeah I did – I did.

I: And so you had a GP that was sensitive to ME…

Julie: Yes, Yeah, Yeah, Yes.

I: And knew that you had CFS. Okay what has other
people’s experiences been like?

Rachael: Everyone’s looking at me so [laughter]. I’ve had
chronic fatigue syndrome for nine and half years. Erm (2)
and my experience with the health service has not been that
good. Erm to begin with it wasn’t that good – nobody knew
what was wrong and they just put it down to the fact that I
didn’t want to go to school. XXX. Erm and you know
because I had ME that’s what started it off. Ehm, I know
some of it is psychological I know that now. (I: Right). And
I know that a lot of it isn’t (1). And a lot of doctors try to fob
it off as being just purely psychological which I know it
126 wasn’t. And my experience, I had a really good doctor as
127 well – she is excellent. And ehm, I’ve been seeing the
128 psychologist for a while now [name of psychologist]. And
129 he’s good – he explains things and helps me to understand
130 things better. And I have come on leaps and bounds. I mean
131 (1) I can’t – I don’t want to go into detail about that but I
132 have come a long way since I was, you know, younger. So
133 my experience with the health care has been both good and
134 bad. It’s just basically whether people or professionals can
135 understand you on a level. (I: Right?) Whether they can
136 really understand what you are saying and take into
137 consideration what you are saying – I think that what makes a
138 good health care professional.
139
140 I: So being listened to?
141
142 Rachael: Yeah. Because they do – a lot of health care people
143 don’t think that [loudly breathes in] it really exists like this
144 lady said – they think it is just something that’s made up.
145 Obviously it’s not! [laughs] Because I mean who would
146 wanna – if I could work nine till five – I’d go every day.
147
148 Pat: That’s what I said. I worked for 33 years and hit me-
149 like- I mean I lost my job because of this. (I: Right). They
terminated my contract— it’s like being sacked and it’s not
very nice.

Rachael: Because people don’t understand, there’s not
enough awareness about it. But I just basically went into my
doctor’s one day and started crying and said “Look, look I’d
rather have no legs!” That’s what I said to her and that’s
when she actually said, “Maybe she is ...”

I: So was this the same doctor that you had initially quite a
bad experience with?

Rachael: No this is a different doctor—we changed because
we moved you see. So even though the doctor before was
fantastic, really, really good and helped me get back in to (1).
Cause I was, I was, I’ve been in I had to stay in bed for like
two years. Well I felt anyway— because I felt too ill. And she
got me back into the open— she used to come to my house
and used to walk me to the front gate, once a week and then
down the road and then back. (I: Right). Eventually after so
long, after two years I ended up doing voluntary work two
days a week. And it’s just escalated from there. But now
I’ve moved because it is quite traumatic moving and
everything it can be quite stressful. The doctor that I’m
seeing now— because you have to change doctors she is not
that understanding. (I: Right). Even though I am seeing [name of psychologist] I still have to go to her with certain problems and she is not that understanding. Until I went in and said, “Look I am trying to say to you this is how it affects my life”. I’m saying, “I’d rather have no legs than feel this bad in any morning”. Some days I feel okay! Some days I don’t.

I: When you said— I'm not asking you for really personal details..... (Rachael: That’s okay). But when you said some of it is psychological and some of it isn’t, I was just wondering what you meant by that?

Rachael: I think what I’m trying to say by that is I got into a routine. Okay I, I got on a bus once and I had a really bad spell on the bus. I had this issue about people looking at me — but anyway that’s a different thing — but anyway something bad happened on the bus, and then I had this psychological thing that every time I got on the bus something bad was going to happen to me. Then it got escalated to like someone would end up killing me on the bus, [laughs] but at the time it feels real. When I look back I think, “Ooh what are you doing you’re such an idiot”. But at the time it’s so real and its like everyone wants to hurt me why? But then when I think back on it I think, “No”. So I try to break that by going
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on the bus even though I hated it – I got on the bus. (I: Yes).
And I’d cry - literally want to cry – but I’d get on it because if
I knew if didn’t get on the bus I’d just end up [laughs] not
going anywhere and I wasn’t going to let that happen. (I:
Right).

Fiona: Very well done there!

Rachael: Thank you, thanks.

Pat: I couldn’t even leave the house for a little – for ages! I
couldn’t face people who knew me, because I looked such a
mess as well as feeling such a mess.

I: Right so there was something about feeling a bit
embarrassed or a bit ashamed about…

Fiona: Because you look fairly normal. Erm, a lot of people,
you know you try and explain that you are disabled and you
can only walk a few feet or whatever- and people are like,
“yeah right, sod off, stop trying to draw attention to
yourself”. And fortunately I’ve had many years and found
myself surrounded by friends, who are very understanding
and realise and are interested in what’s wrong with me but
not to a sick degree. (Rachael: Mmm yeah). But you do get
a lot of, "Oh come on pull your socks up", even from doctors.

It took me (2) it took me three & half years to get a diagnosis by which time I had been – I’d lost my job – I had to drop out of college – I’d therefore lost my flat – I’d spent about six months in squats and sleeping rough – I finally got a flat completely collapsed and been bed-bound for about a year!

Which was nice! And that was- I’ve been ill for eleven years so that’s a hell of a long time ago.

Rachael: You’ve done well as well yeah to get yourself back…

Pat: What I get now though – what does me mostly now is like disbelief as you said from people. I mean I stopped going out – I got a local across the road from me and I couldn’t face going in. And I got to go in, you know, with the help – I did go in with [name of therapist] you know talking to me. Even now people are say to me, “Oh you’re lazy you are. What time did you get up today? Why don’t you go to work?” This has really been getting me down again just lately. (I: Right). It really, really has – it’s what people think about me. I mean I’ve worked for thirty-three years, and you know it’s like, “Oh it’s alright for some they’ve not got to get up for work”. And it just gets to you sometimes, you know, just leave me alone, but they don’t
they keep on at me and on at me and it's though it's their problem I'm not at work, do you understand me, and then I, it upsets me.

Rachael: It's like maybe "you're on disability, you're all right!"

Fiona: I flip out at that point – anger is a gift, anger is a gift. I flip out at enough people for calling me lazy [laughter]

(Rachael: Yes, yes). Thinking that I'm so – I mean I've got so little movement left.

Julie: I go out of my way now to- my granddaughter tells me you know, that sometimes I really look a mess – the hairdresser comes round my house now to do my hair. And I put bits of lipstick on if I'm going out – so to people I'm beginning to look normal again – you know.

I: Right by saying that you are beginning to look normal again do you think there is a link between people saying to you, you are lazy why aren't you at work and all this because you look normal? (Pat: Yes, yes). Right.
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Fiona: I suppose because I’ve had the benefit of being ill so
much longer, I’ve got completely used to handling it. I don’t
always handle it well but …

Julie: Because I know I’m not lazy – I mean I would work
fifteen hours a day some weeks and you know – it’s people
making a point to me and it does get me down.

I: So are these people, your friends, neighbours, family?

Julie: Yes – not family. It was family as well – it was the in-
laws at first. (I: Right). Because my in-laws I think they
thought I was putting on my husband. But how I got over it
the past two weeks – ‘cause I said it was really getting me
down and I saw [name of therapist] last week and she had a
good talk to me a couple of weeks back and I thought, “No,
I’ve been to work and I’ve done my bit. I’ve paid for my
house, I’ve paid my house off – my mortgage – I’ve done my
bit. And this is how I’ve got to keep looking at things to
make me feel as good as what they are – if you understand
me. [Different participants acknowledge what Pat said]. If
not I start going down again, and it gets me down. And
something else will bring me down if I’m not careful.
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II: I’m sorry; I was just wondering what your experiences were at the health service as well? [Directed at the two participants who had not spoken].

Fiona: [Chuckles]. The quiet people.

Collin: I was diagnosed about 5 years ago. It’s took us easily three years to get back on me feet (3) I’m just starting to get back into where I was five or six years ago or something. It’s been a long process. It hasn’t been a simple one, as you say me friends & family and everything they’re all on you (1) “Get up you lazy such and such (1) you know you couldn’t really be as XXX”. (2) But it is cruel (XXX) process and getting back (1) I am getting back, you know, but its going to take a long time to what I used to be like before the illness – you know. That’s the way it goes for me but at the end of the day we all have our ups and downs but just got to on average you’ve got to grin and bear it and get on with it.

II: Were there, sort of - obviously I mean that’s a lot about you doing that, but I wondered if there was certain people I suppose, well professionally that you saw professionally but also in your personal life that kind of helped that or hindered it?
Collin: Well before I was first diagnosed – it took two years
to find out what was wrong with us – I was back & forth to
the doctor’s, “Oh not you again”, and that was their opinion.
“Not you again”.

Julie: It’s awful ain’t it?

Collin: You know, until (1) a new doctor came to the
practice she noticed all the different ailments, and she sent
me to the err, place and I got assessed and all that. Once I got
it, they said you’ve got this syndrome sort of thing and that
was it. And since then it has been a gradual progress, getting
better, better and better - I wouldn’t say I’m 100% but I will
get there – it’s just gonna take time but until I got diagnosed
it was horrendous. You know (2) you would walk in and the
receptionist she would tut, you know you could hear her tut
before I’d even walked through the door. They all thought I
was just putting it on. As you say you know you think at the
time as Rachael was saying, you want to chop your arms off
or something like that. I didn’t want to got to work, but I had
to go to work to pay our mortgage. And when you’re at work
you’re not producing enough err stuff, and they’re on your
back. So it’s all a case of everybody (XXX) just piling on
top of you and then you are trying to swim with a boulder on
you and it’s hard. Hopefully I’m starting to get better but it’s
gonna take time.

**Pat:** Do you get more help professionally now?

**Collin:** Since I’ve been on the programme yeah. He does
talk to us and…

**Pat:** It must have been awful to start off with.

**Collin:** Oh it was horrendous! (**Pat:** Yeah). I didn’t realise
what I had, and that was a problem- in- you feel so ill
sometimes as you say you don’t want to get out of bed- but I
had to get over it because I owned a house so I got to pay for
the mortgage. Even though I was (2) some days I just used to
stand there and just do the work, talk to nobody. My mate
said, “How are ya. He’s got it on again (XXX)”. I wasn’t I
just … I didn’t want everybody just getting on my back. (2)
And then when they come to see you (2) for reviews and
everything (2) it’s “Oh you’re not talking to people you know
you upset a lot of people because you’re not talking to them”.
You know I wouldn’t stop them coming to talk to me (XXX),
(**Pat:** No). And that’s how I got it across. Eventually it’s
starting to get a little bit better – as I say it takes time.
Fiona: It's amazing the people who drop you like a hot brick once they realise you're ill long-term isn't it?

Collin: Oh yes, the friends I had – see I had just moved to the area. I had a small group of friends which I thought were good friends but soon as that happened bumpf! That was it.

Pat: It must have been harder for you say because I, I, I had a good doctor and help – it must have been really hard for you.

Collin: Well as I say the doctors used to say, "Oh well what's wrong now". You know, he used to give me prescription after prescription- none that helped. Until I found, you know, I had certain problems and once I got the booklet and read the booklet it just hits you – don't you think.

(Pat: Yes, yeah yeah). It's me.

I: Yes it's all part of the Rachael thing. (Pat: Yeah).

Collin: Once I read the book...

Pat: Yes I was just saying yeah.
Collin: I’d wasted 3 years sitting on my- well not sitting arse (2) but I didn’t know what was wrong with us. But once you get that information you think well. It just ...

Pat: It’s like talking about you ain’t it? It is really like talking about you isn’t it!

Collin: It is, you think that’s me – that’s me. You can tick them off you know – well that one’s me [laughter].

Pat: Yeah I was the Rachael [laughter]. (Collin: It’s crazy).

I: I wonder how it affects you having people not believe you or to tut when you go to get some help or advice?

Collin: Well it doesn’t bode well on them does it! At the time (1) when I could hear them tutting at me- you feel like hitting ‘em but you can’t. As soon as you confront them you get a letter from the doctor – you are not allowed to talk to people like that – I used to get them - well I’ve had a couple of letters from them.

Rose: I think on a good day it makes you angry like Fiona said, on a good day it makes you angry on a bad day it just makes you want to go to bed and stay there. So if you can
get angry then you are having a good day cause you’ve got
the energy to get angry [laughter].

I: Right and when it’s a bad day you just want to retreat.

[Agreement by all].

Rose: You just want to cry really.

Julie: How did you get help?

Rose: Erm, my experience is similar to Rachael’s really
because years and years of not getting any help from doctors
whatsoever and basically them saying either, “It’s all in your
mind or it’s your age – is what I often got”.

Rachael: Yes it’s your age [laughs].

Rose: It didn’t matter what age I was it was definitely my age
that was doing it [laughter]. So it wasn’t much help but I
work in alternative health so I have a lot of support in that
area and actually have worked with many people with
chronic fatigue syndrome myself and had helped them.

(Julie: Oh right). So basically I turned myself into my own
patient if you see what I mean, and had to work with myself
for many, many years and it is only in the last couple of years

95
since I had a new doctor— who is just wonderful, he is great,
so...

Pat: You two had had it quite a while, do you think I mean
I've had it nearly two years do you think they are getting
better then now in understanding it?

Rose: I still think it depends who your doctor is. I don't
think it is necessarily getting better although I am amazed
'cause I didn't know about this service. Erm, and I would
have thought that I would have known about service through
many of my own patients and not one of them had sort of said
to me that they had any help from their doctor. I have
worked with maybe ten over the years, ten different people
and not one had.

I: So this is not very well publicised.

Rose: It doesn't seem to be to me— but then I'm in [name of
city] so this is a long way from me. (I: Right). It's a long
way for me to come actually to get some help. I think you
know its sort of allowing an hour—, which is not really good
enough for the NHS, is it! [Laughs]...
Rachael: My psychologist comes to me — sorry (Rose: It’s all right). Just to say my psychologist comes to me ‘cause sometimes…

Pat: Oh that’s good isn’t it.

Rachael: Yes. He’ll say do you want me to come to you or do you feel well enough to come to me? (Rose: Well that’s great). And we’ll compromise- even though I’ve not seen him for a couple of months because we’ve been moving and so on but…

Rose: I think that if I hadn’t have done everything that I have known to do over the years…

Rachael: You’ve taught yourself haven’t you? (Pat: Yeah).

Rose: I would have been disabled years and years ago — really I would have, you know. And I’ve sort of pushed and pushed and pushed and tried to get through it, but then in the past 3 years, through erm things that have happened that I haven’t been able to control, it has just got so I couldn’t do it any longer. And then actually that was the time when I got this new doctor who sort of said, “Well how about we look at
this in a different light. Which is great – it’s really good!”

But years of crap doctors [laughs] absolutely crap doctors.

Fiona: I think there are more and more getting switched on to it but it’s still a lottery. I’ve got a doctor who is very understanding about the fact I have got ME but that’s it.

Whatever I go in with now it’s, “Oh it’s the ME”. I could hop in with a severed leg over my shoulder and it’s, “Oh it’s the ME”. [Laughter] (Rose: Yes, absolutely. [Laughs]). I feel. I feel like I need access to more services I know are there, [name of therapist] can’t send me and she’s – the big thing [name of therapist] done for me is just been supportive. we are doing a bit of cognitive behaviour therapy and she’s there when the disability living allowance forms need helping- because the physical therapy we tried made me a lot worse. Erm, but I’m- you know the GP’s just, “Oh it’s the ME go home”. And [name of therapist] can’t send you on anywhere or prescribe anything erm. (I: Yes). The main thing I’m having problems with at the moment is I’m in a hell of a lot of pain- and I’m not sleeping because of it, and I just can’t get anything – I can’t afford alternative therapies – I can’t get to the pain management place that I know there is at the hospital. There is nothing – I daren’t even take co-codamol because I will get addicted to them because I’m eating Paracetamol like Smarties and they would just take
about the edge of things and ... (I: Right). I feel like my GP
is like a bouncer & I can’t go in because I’m wearing trainers.
I can’t get to the things. There is so many little threads that I
need to pull together and if I can pull these little threads
together I’ll be in the optimum place to start going up hill
again. Because I know I can get to the stage where I can
work full time I’ve been there and I relapsed. I got a chest
infection and relapsed, and because I’ve been kind of been
thrown on the scrap-heap at that point and not helped it has
got to the stage where it’s you know every other day I can
perhaps get out of bed. And I can barely walk and I refuse to
use my wheelchair because it’s bloody uncomfortable and I
don’t want my legs to waste away – I don’t know what
happens to legs if you don’t use them – I want to keep on at
them but. (2) Yeah I think with any centres it would be lovely
to have a way that all these things could be in one place and
maybe even a little more local. (I: Okay). Cause it is a hell
of a long way for me as well – it’s not as far as you but I’ve
got to go through sort of south [name of city] countryside
right up to the [name of hospital] on the other side of the city.
And it takes it out of me by the time I see [name of therapist]
I’m insensible. [Laughter] I just gibber at her [laughs]. (Pat:
She’s lovely though). She’s fab.

Pat: She’s lovely she really is.
I: So far from what you’ve said I guess there’s this sense of having quite a rejecting experience with some GPs – some GPs are really good as you pointed out but it’s a lottery it’s a hit and miss kind of thing. And then you’re analogy of the bouncer. So I suppose if you have a GP who believes you have ME - but that’s not it, there’s another layer there’s another hurdle to go through and to get what you think you need.

I was thinking of the therapeutic relationship you are in and you have already touched on it quite a bit actually. Talking about being supported being listened to and some of what you were saying Pat, almost like being kind of directed as well in the sense that you say [name of therapist] has reorganised my life…

Pat: Yes. Well actually I suffer with my back and everything and it’s like you say it’s expensive to keep having these things done. And it’s - like I pay £30 a time to have me back all done because, like you say your body aches and that- and she’s been lovely as well (name of therapist) and err, she’s an occupational therapist, and I’ve bought some in-soles from her they did cost me £50 but they have got little magnets in and they do – you might think it’s all in the head but they do help me – they give me – they magnet parts of
your feet and they do help my body. But as you say things
are so expensive you know – you do try to help yourself –
anything if you can.

Fiona: If I knew something was gonna help I would drive
through wild horses to get it.

Pat: This is why I bought these – this is why I bought these!

Fiona: Anything that’s gonna help - that’s another thing I
can’t get access to NHS - the people who do orthopaedic this
and that like cushions, in-soles – I really need a cushion
because my … tip of my coccyx is screaming I’m actually in
lot – like pain right now and it’s these little things that erm.

Pat: I’ll show you these [takes in-sole out of shoe to show
others] and they’re like shaped- they’ve magnets on the back
and they magnet parts of your foot to help all your body.

Fiona: Like acupressure almost.

Pat: And they do – yeah – honest they do help. I find them
really helpful.
Fiona: I mean I have spent like 600 quid on a mobility scooter because I knew it would help. 'Cause I knew it would help I could throw that money at it. Erm, I got some disability living allowance back-pay and it's a godsend 'cause it's the only way I ever get out of the house and it's only perhaps once a fortnight I manage to get out. But you know could pootle round the block and it's better than nothing. (I: Mmm)

Pat: That's not how you want to live is it?

Fiona: Well no (sighs). I know it will get better though I don't know how long it will take – I wish I did. That would be the thing if it was like, "yeah six months and you'll" would be cool. That's impossible isn't it – you can't say that!

I: I mean there does seem to be a lot of uncertainty about ME and knowing how long you are going to have it for and how to cope with it. I just guess there is so many things like this works and that works et cetera and it's an individual thing isn't it? Some things work for some people, some wouldn't work for somebody else but ...
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Pat: Well we don't know what causes it - people say it's a virus, somebody else like Rachael say it is psychological, I mean you get all these different things off people as well (agreement by all). I still don't know what causes it now?

I: I don't think there's an agreement on ...

Rose: There is some research that says that it is often triggered by a blow to the base of the spine (2) by a fall or...

Fiona: I haven't read that

Rose: or something. I did, I know this is not part of your whatsit [looks at main researcher] but I would actually be interested in anybody - did anybody have a blow to the spine at any time - the base of their spine? (No by all)

Pat: Not before this come on - I did have my gall bladder out and I caught a, I got a virus but I mean this is - I don't know.

Fiona: XXX then I got glandular fever didn't get better but I don't think they were connected though [laughter].

Pat: Did you have you?
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Rose: Yeah I did I fell off the ladder. (Pat: Oh dear).

II: Can I, sorry to distract you, I know Rachael you were saying of how when you see a psychologist that you sort of erm will swap about who comes to who- and you were saying about the spirit of compromise is that something that may be particular to your relationship with the person you're seeing or (Rachael: Erm (2)). Or is not? It just sounded like as if you found that was quite helpful?

Rachael: Yeah I think it was all I was trying to point out that it is good to have that option.

Fiona: I'm very envious of you here because I - this is my access is my bugbear. I have access to nothing - my glasses are falling apart, I can hardly see - my teeth ache and I can't get to anything.

Pat: How old are you? [Directed at Rachael]. (Rachael: I'm twenty). Twenty!

Rachael: I make a big issue of everything though; I don't let it just go. They say, "No you have to go to them", and then I'll take it a step further but I say, "Well, you're not disabled
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are you? So it’s alright for you to say that to me”. That’s the
kind of thing I’d do.

Rose: Do you want to call mine [laughter]?

Rachael: I do though, I make them try to realise that this is
what I have to go through every single day – put yourself in
my shoes – not that you ever could but …

I: But I guess you have to be fairly assertive

Rachael: You have to be firm, if you’re to get anywhere you
have to be firm- because you don’t get nowhere. People
don’t listen to you unless you tell them – “this is what I am”.
It’s like when I used to work – you can do so many hours
working with the disability- I basically told the boss well
alright – yeah you can have the job but what I’m saying to
you some days I won’t be able to come in – do you
understand that… (I: erm). Because that is who I am – some
days I won’t be able to come in because of my disability – I
know now they can’t discriminate against you [agreement by
all] – but it is still quite hard to explain to your boss – I can’t
carry that heavy box from there to there. I can’t carry those
boxes.
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692 Fiona: I've never had an employer who has understood.

693 (Pat: No I've not). That helps the relapse to be honest.

694

695 Rachael: Yes it does definitely - luckily college is brilliant!

696 (I: Right). I go to college now - they are good anyway.

697

698 II: Sorry to interrupt I'm just aware of the time.

699

700 I: Shall we stop there because it is important that we finish
701 by four? Is that okay, say 5 minutes.

702

703 BREAK

704

705 I: Right we've just had a quick chat and I am sure everyone
706 else has had time for a chat and a think but - some of the
707 over-riding themes that are coming out at the moment are
708 being disbelieved and what impact that has on your sense of
709 self. There is this fight and the need to really be self-reliant,
710 to be heard [nods of agreement]. And also I know that from
711 what you said the importance of losing your job, financial
712 constraints. As you were saying Collin, and I am sure this is
713 other people's experience that you have to pay your
714 mortgage. And these are really important things that can't be
715 overlooked but I just wanted to for the last half an hour is just
716 to focus basically on relationships in the sense of your
relationship with your therapist. I know Pat you said some
things about it – you all have in different ways. What do you
think, what for you are the really positive factors out of your
relationship with your therapist – if there are any?

Fiona: Just the support – I think the support is the big thing she can do for me. (I: Right). As she says if you need to
phone up phone me up – I’m here a lot such and such time
and just phone me up.

I: So that’s somebody in your corner?

Fiona: Yes absolutely! And I’ll say “Ooo, I felt a bit rough because.” and she’ll sort of finish the sentence, and I think “Oh my God”.

Pat: She has become a real friend really, as well. (Fiona: She has).

I: How would you – thinking more about that what would make someone a friend?

Pat: Well believing in you I suppose and really trying to help you. (Fiona: Yes). The best she can.
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742 Fiona: It's that understanding, constructive understanding not just, "Oh dear poor thing ahhh" – constructive understanding.

745 I: Yes okay. What have you made of it [looking at Collin]– sorry to put you on the spot Collin, [All laugh]. In terms of –

748 I mean is there anything useful that you have found from ....

749 Collin: As you said it's the general understanding of what you go through. I read sheets (2) and he assesses all the sheets (2) and you tell him I was doing such and such, you know, I've increased the walking this morning to err, like jogging now – so you're not just going out and running for an hour – no, no no just 30 minutes – it's best if you knock it down to 20 minutes or something and then start gradually building up. (I: Okay). It's an understanding what I am going through.

759 I: And setting realistic goals

761 Collin: Yes he sets us goals every month or so. When I've been bad in the last couple of months and I've shot myself in the foot, I haven't really done anything except now I'm starting to do a little bit more so. (I: Yes). Because as I say I have my ups and downs, last couple of months I've been down a little bit and still I can come back up a bit.
Rachael: It's the weather

I: Yes there is something about consistency that in a way you have got someone to see that's providing some consistency in reviewing how you progress?

Collin: Sort of, well you know he's in, as you say he's in your corner, sort of thing. I get a chance to talk things through with him and he will criticise it and say, “have you been on the run”, sort of thing but I haven’t really run for about six years now or so. (I: Right). So I’ve gradually built my running back up.

I: Right okay, so he is using things that you’re interested in as well, ‘cause I was just thinking I suppose for somebody else if running wasn’t your thing – I mean I would be horrified if someone said to me to run. [Rose laughs]

Pat: Oh no they tell you to try to find an interest. Like I walk dogs now. (I: Right). She asked me, “What do you like doing, there must be something”, and I love animals – I just love animals. She said right find yourself something to do with animals- and I do it voluntary walking dogs. (I: Okay). I’ve had tapes off her – relaxation tapes as well – you know
she does – if you’ve got anything and you ask her the next
time and she’ll try and sort it out for you.

I: Right so it’s real practical help as well (everyone agrees).

II: Is that sort of true for other people as well – it sounds
like the practicality – you know that there is some practical
stuff – are there any other sort of things that maybe haven’t
been mentioned that may be helpful?

Rachael: [name of therapist] he just really gives me sheets to
read. I don’t think he is really up on what’s going on. He’s
good don’t get me wrong and he has helped me a bit but he is
not (3) he just gives me sheets to read basically and fill out a
diary and stuff like that. I don’t think any of it helps! But he
does give me advice but not any that’s really going to change
me that much. I have always been self-help, that’s what I’ve
found. (I: Right okay). Cause (3) that’s the only way that
I’ve ever found anything useful in reading books- but he has
been a bit good in some ways. I think if you want help you
have to kind of find it out yourself. (Pat: Yes you do). It’s
like college- I had to go and tell them I wanted to do this
course, I mean I’d love to go to university- in reality I don’t
think I will be going. One I can’t afford it because I’m on
disability and two I don’t think they would cater for my
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needs. (I: Right). But I would love to go – but luckily at college they are quite good and understanding. But I have had to go forward and tell them can I have extra days to hand in assignments, can I have a support worker! And I have had to do it all myself.

Pat: This is it- with other disabilities you get that help don’t you. (Rachael & Fiona: Yeah). But with this one – this is it – you don’t seem to get any other help. (I: Right). It’s like if she’d got one leg or something – one arm – they would give her help or if she were deaf- but because they don’t see this as a disability she doesn’t get any help.

Rachael: It’s because you can’t see it!

I: I think that actually taking what you have just said very concretely there is something about not seeing isn’t there – for example, your arm is not in plaster – perhaps other people struggle to understand. I was interested in this thing about Fiona I think you were saying you having CBT, and I am aware that some of the treatments you are having are different to that. I guess yours would be along the lines of cognitive approach as well [directed at Pat]. I am interested as well Rachael, I guess what [name of therapist] was giving you would be part of particular type of approach. (Rachael:
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yes). Which doesn't sound like you are finding that helpful… (Rachael: It's not) From what you've said.

Rachael: Not really. I've just got kind of to the end of being bothered with it now. 'Cause everything is — the thing is —
you know I've been to doctors I've had all these tests— none of that ever helped — different ways of thinking — yes some of
that has worked but some of it doesn’t.

Fiona: It doesn't actually help the ME I've found. (Rachael: Yeah). It helps the misery that happens because of ME or it can do, or it can help you think positively. But the actual ME (2)— you know I was absolutely fine mentally before this —
there was nothing wrong with me — you know I was a figure skater — it was brilliant and then crash right down...

Rachael: It's like me I so badly wanted to go out — I wanted to be an actress - my mum paid for me to go to acting school and everything — I went for years and years and it as just like (2) turned around and everything was gone — that's what it felt like — felt like the whole world was just empty — it was just me and everything came crashing down.

I: It sort of sounds like you have been robbed of something. (Rachael: Yes. Fiona: Absolutely). I think they are both
interesting points- where this approach perhaps doesn’t really affect the condition as such it’s more your sense of self?

Fiona: Yes it is vital I think to actually keep that sense of self because it is very difficult getting back into real life in adverted commas. You know, when you have spent the last three years in bed and suddenly you are looking at the job – it’s terrifying.

Rachael: There needs to be more help with that – I think.

Fiona: I think so I mean I wouldn’t go- I went on a new deal for the disabled last time I was well enough to start work again and they were useless. And I know they are looking at doing a little more now. But I wouldn’t trust them so far as I can throw them- because I know so many people who have been through new deal on one basis or another and they’ve been sent to these training places and it’s all so inappropriate and they don’t make any effort to understand individuals’ needs. (I: Right). It’s just farmed out to these companies via the job centre and nothing to do with the job centre and… (I: Right). I’m an IT Consultant, “Well go and pull pallets around in a warehouse then for six months for no money”. That sort of thing.
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I: So again there is something superficial about that about
that – superficially doing something but actually not listening
and not understanding.

Fiona: Yeah, it's all show- it's all mouth.

Pat: Well if you're on job seeker's allowance you can claim
loads of things but if you have got ME and on incapacity you
can't.

Rachael: It's not a means-tested benefit. I've got to pay my
rent at my flat – I've got to pay the full rent. [All agree].
Because it's not means-tested.

I: So I suppose what we are talking about at the moment is
very broad, it's about how society copes with...

Rachael: Yes it would be nice if society knew what it was
like. (I: Yes...). Yes obviously there's loads of ignorant
people – there's loads of different people in the world- in the
country- who have different ways of thinking about
everything. You know, down to the way a house should
look! But it would be nice if people were more aware of
what chronic fatigue syndrome is – I mean if the health care
doesn't know then who does know?
Pat: We want to work and can’t – a lot of people – don’t get me wrong – a lot of people on job seeker’s can’t find a job. But some of them on job seeker’s can work and they get treated better.

I: Right, okay – so if we just step back again a little bit. I am aware that – I mean what other factors about your I guess therapeutic relationship are helpful or not so great?

Fiona: I think [name of therapist] and I are a little frustrated at the moment with me- butting our heads against this wall of she can’t offer me any more treatment that we can’t get any further forward with what we are doing until I get erm three or four problems sorted out. Like the chronic sinusitis, the joint pains I suffer, my sleep problem – we are working on the inevitable depression that you get from being incredibly ill and getting absolute no sleep. But that’s the only thing we can do. We’re here, we, I mean we both – it’s nice that she feels frustrated with me, but we are both very kind of head against a brick wall at the moment erm. We’ve given up on the graded exercise thing because it made me worse. (I: Right).
Rachael: Self-help can work! It can. To a certain extent better than any doctor.

I: What would that involve?

Rachael: Just positive ways of thinking – like I was saying about the bus. I am not gonna let it – it does take over my life – but if I think it's not going to. I try and make my every day be like normal. Sometimes it's not and sometimes I overdo it – I mean I'm twenty and I wanna go out and go clubbing and I can't do that. I know I can't do that- but self-help is good you know – pacing yourself.

Fiona: You're doing it for you aren't you, you're not being forced to do it by some great big therapist – you're doing it for you. (Rachael: Yes – that's it). That's how you've got to do it! If you don't do it for you- if [name of therapist] with a cattle prod she wouldn't be doing any good.

Rose: It sounds as if- I saw [name of therapist] once, and she said, “It sounds to me as though I can’t actually be of any help to you, because you’re doing and have done all of the things I would do with you. So I am going to pass you over”. But it sounds as if [name of therapist] has done like the absolute best as far as not putting everybody into a category-
because there are as many types of chronic fatigue as there
are people, you know, everybody had got such a different
experience- even just around here. I found that was the most
frustrating thing- of seeing a doctor and the doctor saying,
“You must do this”, and sitting there knowing that that’s not
gonna be right for me. [Laughs] And you’re not listening to
me. You know sort of- I mean I’ve had one doctor say to me,
“You must you absolutely must stay awake all day and not
give in to going to sleep”. Well if I did that I would fall
asleep at the wheel on the way to work literally. You know I
would kill myself because I wouldn’t be able to stay awake.
Ehm, and that’s been a frustrating thing is people thinking
that they know what’s right for chronic fatigue sufferers in
this you know big, you know thing! And somebody like
[name of therapist] sounds as though she is working
individually with this is right for you and you saying about –
you know your running and whatever – and you saying
somebody told you to run and you saying “What!” [Laughs]
But yeah it sounds as though that’s the starting point of
actually making progress for anybody isn’t it? Of actually
being treated like an individual and being listened to.

Fiona: And by finding that suits you as well.

Rose: That’s right. Is she from the Hospital?
Fiona: I did find it a little hard work- I usually have to tell [name of therapist] two or three times if something’s say not right or I’d like to do something. But I think that’s a good thing in a way because it means that (3) say I felt something was harmful and she knew I would pull out of it if I stuck at it. She’d not say, “Give up” when I feel like giving up. I do feel I have to push a little bit I mean I don’t know if that is normal – it’s the first time – I’ve only been seeing her for about eighteen months – it’s the first time I’ve had any treatment at all in any shape or form for ME. I don’t know if that’s how it goes – that’s the only thing I’ve found I do have to push a bit – I do have to put my foot down a little bit. She’s very good about it she doesn’t kind of see me as a difficult patient-, which is something I feared very strongly. As if I kind of say I kind of being doing this for six months and I can hardly get out of bed now will she think, “Oh well this is stupid she’s just not going to co-operate is she”. She hasn’t done – which is bloody good. (I: Right).

Rose: I really fear that to - that’s interesting - I really fear that that somebody is going to think I’m a difficult kind of patient.
Fiona: I had what you had with the doctor "Oh bloody hell not you again" sort of thing and you know she actually got quite nasty with me but fortunately I moved about three months after and I got a different doctor who just didn't give a shit, you know just didn't care you know — it's just like "Oh its you again go and take paracetemol".

Rachael: Oh I'm just like oh you get paid sort it out, I'm telling you I'm not well — I don't give — I've got no sympathy at all. If somebody doesn't want to help me I'll tell them. You have to be firm that's the only way I've ever learnt. Not to be aggressive but to be like you know, "I'm telling you I'm not very well listen to what I'm saying, you get paid for this, you have to listen you have to help me, you cant just fob me off with some antibiotics". Cause I won't let it. I'll keep coming back — I will make an appointment every day if I have to and I'll keep coming back until you help me. That's the only way that sometimes you feel like you are getting through — see what I mean.

Fiona: [name of therapist] just helping me get to this stage because I am very, I have become very submissive in that way because I have just been everything from fobbed off to abused in trying to seek help I have just given up. (Rachael:
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No you shouldn’t. She’s getting me back into stamping my feet a bit.

II: I mean it sounds like from what you are saying Fiona that there is something also in sort of those maybe all relations but you have talked about the professionals about sort of being able to be honest with someone and their being honest with you, like when stuff isn’t working that you can actually say, “It’s not working”, and someone will be responsive to that or certainly receptive to it and maybe try and think okay right and not just keep going on. So I wondered is that true for other people.

Pat: She’ll listen to anything- it might not be to do with ME – she sorts it out herself – with even family things – she’ll ask me about you know if she thinks it could be something like that. It’s not just me- she talks about my family as well and how it affects them. (I: So it’s in context). Yes she gets involved, you know, not with just me you know.

Fiona: She’s the first professional that I have been able to do that with I am not sitting scripting how can I go in looking so this person will give me treatment for the illness I’m going with and not just fob me off because it’s ME or how can I look more ill. You know I can actually go in – she knows the
I: Yes there’s something about being accepted then really isn’t there that you can present as you are and you don’t have to sort of do whatever you need to do to get help in other forums.

Fiona: Yeah make sure I haven’t washed my hair for a couple of weeks and ruffle it up a bit before I go inside to look as if I’m really need of, in need. I’ve done that before I am ashamed of myself, [laughs] cause I’m no good at stamping my feet. I have to put [I: Right] it on.

I: I just want to go back to this thing about the fear of being perceived as difficult patient. How would you make sense of that?

Rachael: I think that’s about from having bad experiences with doctors. (I: So do you think…) ‘Cause you automatically think, yeah, their gonna think I’m a bad, erm you know, a difficult patient. ‘Cause I’ve gotta try and explain from, you know what’s happened in the past and do they understand? And can they really help me? Or do they think I’m being annoying and…
Fiona: Mmm. I think there’s still an issue that when you go into a doctor and say, “I’m ill”, and they’ll go, “right take Paracetamol, go home and have a rest”. You come back a fortnight later and you’re still ill. And they’re like, well what are they after? Are they jockeying for drugs? Have they got Munchausen’s Syndrome? Are they jockeying for attention?

(Rachael: [Laughs]. Yeah that’s true!). Do they want tea and sympathy? Are they lonely, do they want a chat? Are they after anti-depressants to sell...

Rachael: Do you wanna see a counsellor- always! [Rose laughs].

Fiona: Right, right. It was hilarious I’ve had times where it has just been assumed that I have been after tranquillisers to sell, [laughs] which is nice!

I: So you have been judged. (Fiona: Yeah). I’m wondering whether there is something about the difficulty professionals face when they don’t know what to do? (Emily: Oh absolutely!)

Rachael: That’s why it’s always put down to it being psychological; ‘cause there’s not enough research and
awareness into Chronic Fatigue Syndrome. [Sighs] People don’t just get ill, I mean, there’s got to be some underlying thing. [I: Mmm] I just think it can’t be psychological, people love to fob it off as being psychological, for me, that’s my experience, I’m not talking for everyone, but for me that’s been my experience. [I: Right]. Some of it is okay, I think, some of it is, but some of it…

Fiona: I don’t think you can have an illness like this and not have psychological problems!

Rachael: No. I mean some things are psychological, you know, when people go through trauma, and they get paranoid, and things, you know, bad things I can understand that it probably is psychological, a lot of it, and people do actually get over those. But I mean, nine and a half years, I think I would have been a bit bored of being [laughs] you know what I mean!

Pat: Well you would have pulled your socks up wouldn’t you!

Rachael: Like I said, going to university, do you think I’d wanna jeopardise that for being on benefits!
Fiona: I mean they act as if benefits is wonderful, it's like,

it's bugger all, it's you know, I'm supporting me and a carer

cause I'm not allowed a carer, so I've got to support

somebody on my benefits, two of us. I've been sleeping on

friends' settees for the last three years cause I can't have a

carer and somewhere to live. You know, and they're like,

“benefits are great, everybody wants to be on benefits 'cause

it's so brilliant!” And it's like, who in their right mind, when

you can get a job, you can get a basic minimum wage job and

get three times as much per week as you would get on

benefits just for showing up, not even having to do anything

too difficult or strenuous...

I: Okay, there seems to be a difference between how you

thought and constructed yourself before ME, and what you

have had to think now? [Two participants murmur in

agreement]. I guess you may be forced to reconstruct

yourself?

Fiona: Yeah it's quite a painful process that forcing of your

brain into that different shape. [I: Right] It feels, you

almost melt and crash, and then pull up. You kind of, you

end up, I mean I, I attempted suicide twice and then, at that

point, it was like, “Okay, I'm ill, I can't get a diagnosis but I

know I'm ill, and whatever anybody else says I'm not taking
the piss”. And I know it’s not the right either but, you know
like, “I’m a bit depressed and I’ve got a brain tumour and
they’re not telling because I might top myself” you know,
cause thought that might be it. You know I thought they
thought “Oh she’s got depression and if I tell her she’s really
ill, so I’ll just say there’s nothing wrong with her and send
her home”. I don’t know, I don’t think they really do that do
they? Well I was seventeen and terrified, so, but I was a
complete flat pancake at rock bottom, and you kind of
reconstruct from there in the sort of ME shape, as it were.
And yes I am ill and everyone else has got to bloody well
cope with it. ‘Cause I can’t do a damn thing about it, and if
they don’t like it then they can piss off!

Rachael: It would be nice if there was a group you know,
like this [Rose: Mmm], like this, but was ideal for everyone
to get to. [Fiona and Rose: Yes].

II: I’m surprised there isn’t?

Rachael: I think that would be good that would.

Fiona: I think there’s a [Name of City] ME Group who, I’m
a member of Action for ME, I try and keep up with the local
groups and the current research- erm, and they’ve got no web
presence, they don’t seem to be in any phone books, I’ve seen
a poster somewhere but I can’t remember where, one solitary
poster. They seem to have such a low profile presence and I
don’t know whether that’s deliberate or not, ‘cause obviously
people with ME, they don’t wanna be inundated ‘cause
they’ll be too knackered to cope with it.

Rose: Yeah! It’s probably set up by private individuals that
just want to have a support group so...

Fiona: And it costs money.

Rose: Yeah it costs money yeah, and it takes a lot of effort to
advertise things, and erm... (Fiona: But if they...). And the
energy’s just not there to do it!

Fiona: But if they just contacted AFME [Action for ME],
and just gave them the details they would put them on the
website, and I get the ‘Interaction’ I get the bimonthly
journal, and it would be in there, it would be get-at-able, and
that would be free. I mean, I don’t know, I mean it just takes
somebody being a member of AFME and, being a member of
the group as well.
Rose: I just before, I mean, because I have to go at four o’clock but I think all the important things is this thing with psychological and the physical, because often doctors get to the stage where they say, “Oh it’s psychological”. Well actually, as Fiona said, you only have to be in pain for a short period of time before you’ve got psychological problems [laughs]. You know, you have got problems, you either got depression or, or, you’re wrapped up in some psychological thing. And I think that’s frustrating that doctors do seem to actually negate everything that’s gone before, how you got to where you are and say, “Well you do have psychological problems with it”. (Fiona: Yes). Okay I do, but I started off with pain, not being able to get out of bed and all of that. But for me, being here in [name of building where Rose has therapeutic sessions], as I haven’t seen [name of therapist that has seen Fiona and Pat], well actually that’s, for me nice to have somebody that appreciates that, “Yes we do have psychological issues to work through and I also know, I’m listening to you, that you have all that pain and everything else, and possibly that started first, or maybe, shall we look and see whether there was anything before that? There might not be, but let’s look at it”. It’s that openness which for me is important.
I: So important that someone is honest (Rose: Yes) with you about their position.

Rose: That's right. And them not saying, "Well I'm suggesting that this is how it happened", because they don't know, they have got no idea, but "let's explore it together".

Fiona: Well you get ten minutes for a doctor's appointment, what can you tell them in ten minutes.

Rose: Exactly, yes. Because you want to tell them what happened ten years ago, don't you?

Fiona: I've been through all sorts of stuff symptoms-wise, and I'm still getting new symptoms, and knocking old ones on the head, I mean, it's still changing. (Rose: Mmm) And it's been eleven years now, nearly twelve!

Rose: And you can't get any help from a doctor when you're going in with today's symptoms because that's not gonna help at all, 'cause it has to be seen in the whole picture.

Rachael: It needs to be holistic yeah.
I: I guess as well it's also difficult to convey the whole picture to the doctor, because of yes, the limited time frame but also because of the cognitive effects of having CFS.

Fiona: Even writing it down don't help cause the letters swim in front of my eyes, I can't read it. (I: Right). 'Cause I've developed a bit of a panic disorder since the last relapse, what with one thing and another, and I was so high by the time I went to the doctors I can't read the bloody thing.

I: Okay, I don't particularly want to continue the group discussion without Rose. So is that okay with everyone that we still finish at four, I know it feels a bit rushed [participants nod in agreement]? I would like to thank you all for coming I know it has been a long way for some of you. I have found it very interesting today, and hope you have also got something out of it.

Pat: I think it's because we all want something done about it we've come.

Rose: You're right [other participants say “yes”]
Rachael: I don't mind if you ever want to, again talk to me.

(Fiona: Yes me too). I'd be happy, more than happy to help you with your research for Uni, and stuff like that.

I: Thanks very much. Is there anything people want to say briefly, bearing in mind the time, is there anything burning that you feel you had not had the opportunity to talk about today [looking at Collin].

Fiona: [Laughs with Collin] you're on the spot again!

I: [Laughs]. Okay let's start at the other end of the circle.

Fiona: I've pretty much spat out the couple I wanted to, I'm okay.

Pat: I think it's done us all good to be here today!

Collin: I think so too. (Pat: Yeah).

Fiona: Yes, I've never met anyone else with ME before [laughs].

II: That's something in itself isn't it.
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Venue: Activity Room at the Cedars Centre, 5 Participants

1309 **Fiona**: Yes, it's so isolating. It's unbelievably isolating.

1310

1311 **I**: If I find out about support groups do you want me to send you the information? [All participants indicate that they would like this].

1314

1315 **Rachael**: I do know one, it's AYME [Name of organisation] they only deal with people up to twenty-five…

1317

1318 **Fiona**: Yeah, I'm aware of them, and they're excellent but I found them when I was twenty-six!

1320

1321 **Pat**: Well I've had it then [laughs with other participants].

1322

1323 **Fiona**: I know a couple of Internet ones but that means sitting on a computer for hours on end, your arms start to…

1325

1326 **Pat**: I wouldn't know how to use one!

1327

1328 **Rachael**: All I can say is that I do know someone who had, erm, Chronic Fatigue Syndrome [person's name] and he did get better! And he had for seven years.

1331

1332 **I**: Okay, so there's hope? [Facing the remaining participants that had not spoken]. Is there anything that you wanted to
add or say differently? [Participants shake heads] Okay well

thanks again for coming.

Rose: Thanks it was good meeting you all. [Remaining participants respond].

Rose leaves the room with the Investigator. The remaining four participants remain in the room, and three complete their Consent Form and Demographic Information Form and continue to chat informally. Pat talked about how her daughter had initially helped her overcome her symptoms by introducing her to a friend who had CFS/ME. Pat then talked about how her daughter and herself followed the friend's advice to begin the process of managing her CFS/ME. Fiona talked about how she motivates herself to manage her symptoms. Rachael reinforced the importance of not giving up and thinking positively, as she acknowledged that your behaviour impacts on others around you, in the sense that they give up too. Rachael also stated that she feels that CFS/ME has been a positive impact on her, and that she may have been a different person if she had not had CFS/ME. The remaining participant stated that she would return her form in the post, and seemed to be waiting for the others to finish so they could leave together. She then looked at the forms, and decided that she would complete them as well. Two participants exchange telephone numbers. As they leave they laugh and joke about the probability of meeting again during a protest for fighting for the rights for people with CFS/ME.
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I: Basically what the group discussion is focusing on is your relationships with the Health Service, so that includes GPs and your therapeutic relationships that you’ve had – that’s with [names of therapists].

I will be writing up the results of the group discussions and looking to publish it. In terms of letting everyone know what the outcomes are, I am thinking that the easiest thing to do is to write a short report and send it to you. I was originally thinking of doing another presentation but just arranging the groups has made me think that it’s going to be hard to get everybody in one place.

Kay: You can’t please everyone can you – it’s difficult.

I: Yes and like both of you – you both live quite far away, so it means there is going to be the journey as well. So wherever I do it, it’s going to be a long distance for some people. Well see what you think, you can always leave a message for me on the university number I gave you.

Kay: That seems fair enough. (Kerry: Yes that’s fine. Mark: Yep).

I: Yes, okay. In terms of ground rules, because this is a confidential group, I think we need to sort of protect each
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other really, so what’s talked about in here doesn’t go outside
the room. **Mark:** Sure. (**Kay:** That’s fine. **Kerry:** Yes).

Have you got anything else that you would like to add to
that? (**All:** No).

**I:** Okay. Is there anything else we need to establish? We’ve
talked about timing – I’ll make notes because it helps me to
focus on things as well. So basically the three things that I
would like to cover today. Firstly, thinking about your
therapeutic relationship. Secondly the sort of relationships
you have with other professionals in the NHS, and thirdly just
basically thinking about relationships more widely, in terms
of what it means to have CFS and to engage in a meaningful
relationship with whoever. Does that make sense? (**Kay:**
Yes very much. **Kerry:** Yes).

**I:** Okay so has anyone got any questions or is there anything
that is unclear? (4) So if we make a start, you have all had
some different forms of therapy. I know you haven’t all seen
the same therapist but thinking back now about your
experience of the therapeutic relationship, what did you make
of it and what are your reflections about it now?

**Kay:** I found it quite helpful talking to [therapist’s name]
because I think people perceive you differently – I don’t
know whether that makes sense. Your friends look at you
sometimes as if, because, if you’ve got a broken leg they can
see what it is, but people find it hard to know what is wrong
with you, and to understand that you are in pain, and because
you don’t look ill [Mark: Yes] that’s the hardest thing isn’t it.

Kerry: Because they can’t see something.

Kay: Yeah. If you, if you got your arm taken off – you’re
not looking for sympathy I’m not saying that but people just
don’t understand.

Mark: There’s a bit about sympathy and understanding.
You just want to be taken seriously.

Kay: And I think the GPs are absolutely disgraceful.

I: Right and that was your experience with it?

Kay: Yeah. Because I was diagnosed with it about 6 years
ago, and my doctor sort of pooh-poohed it – I’ve got another
doctor in the practice now and she is quite good with it
because her sister has got fibromyalgia. (I: Right). But I
went one day when I was really at a low ebb, and my doctor,
who we know personally as well – he’d had a bad day
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obviously, and he said I’m really knackered today Kay, I’ve
been doing the garden all day – do you think I’ve got
fibromyalgia? And you could just turn round and think
“What!” [Sighs].

I: Yes that’s dismissive isn’t it?

Kay: Well it’s like a slap in the face isn’t it? (Mark: Quite
appalling really). And I went home in tears really – ‘cause I
thought well he obviously doesn’t know and understand how
I feel – it was just like a joke. [Everyone mutters agreement]

I: Why do you think he did that? What sense did you make
out of that?

Kay: I just thought he thought he was being clever (I:
Right). He’s got that sort of personality. (I: Right). I
thought ‘cause he thought ‘cause he had a few aches and
pains from doing the gardening, he made, he made it seem
like a light thing to have fibromyalgia. (I: Yes). Which it’s
not it’s life-dominating…

Mark: If you had gone in with cancer he wouldn’t have
make a joke about cancer. (Kay: That’s right). It seems to
be an easy, you know, there’s certain conditions that…
Kay: It's like a cop out. (Mark: Yeah)

Kerry: As you say actually my GP, erm, said that ME was caused by, erm, people that had flu, they didn't exercise enough, and they were lazy basically, and that's why they felt tired. (Kay: Yeah). But erm, my dad actually went into the same GP and he had, 'cause he was diagnosed with cancer, and he was very very understanding with him and very sympathetic. He had no sympathy with me whatsoever. (I: Right). So I think because that was tangible and he could find a blood test for him. (Mark & Kay: Yeah). And you know, with ME you can't - it's just a matter of you know, "oh you haven't got this or this - so you must have ME."

Mark: My, my biggest annoyance, I know getting off the topic, but it's slightly a different tangent, but the most annoying thing I find is, is that erm, (2) [laughs] What was I saying? It's like I don't remember what I was talking about. Erm, its the thing that, it's the kind of people it affects, most people - I mean I have never been part of an ME group but I was invited onto an Internet forum, and I sort of chat with people with ME on there. Erm, and most of them are classed fairly young, and got ME or CFS through or around the time of "A" levels or through sort of working really hard and stress. And erm, the other people that I know through, from
sort of general life, got it - one was an Ironman tri-athlete, so

not just like a normal tri-athlete. I was a long distance runner

and a semi-professional footballer, you know. Most the

people I know are not naturally lazy – that’s the thing that

annoys me is that they are not lazy they are people that

actually did the opposite [all agree] and that didn’t rest when

they had virus and things like that. (I: Right).

II: They tend to be high achievers? (Mark: Yeah)

Kay: I was a landlady for 20 years, and I think the worse
thing when I was diagnosed with it I felt as though I had no
self-worth – I wasn’t pulling my weight in the partnership but
my husband was sort of carrying me workwise. And you’ve
got that awful guilt feeling that you can’t do, and why can’t
you do it.

I: And especially as what you are saying ‘cause you have all
worked really hard…(Kay: Yeah, yes). Anyway you were
saying you’re very sporty … (Mark: yes)

Kay: It’s the same thing isn’t it? No – they are hard working
like you were saying [looks at Kerry] like the exams and
that… (Mark: Yes)
Kerry: Well I got it when I was doing my GCSEs.

Kay: So much stress and, you are working so hard aren't you and...

Mark: I think it was, when it got, I don't know about going back before the seventies but I remember in the eighties it was Yuppie Flu. (Kay: That's right yeah.) And that's kind of, well, well that's not going to do any condition any favours is it! 'Cause you know, people aren't particularly sympathetic towards yuppies you know - "a load of rich people are getting ill - oh well that's their problem," sort of thing. But, but that also kind of proves that it's people who are burning themselves out in a way. And personally I mean I was working, I was doing a long commute - I was working at [name of newspaper] and you know, in the mid-nineties I was playing semi-professional football, I was playing Sunday League Football - I was doing 5-a-side - my life was just absolutely chaotic.

Kay: So you wasn't a lazy sit-about doing nothing.

Mark: No I wasn't! But then I - you know - and then I had to go through like when I'm in my sessions with [name of therapist], one of the things she put to me was that, you
know, psychologically would you be wanting to avoid. You know, cause she was going through all the, you know, all the psychological aspects of it. And you know, is there anything you want to avoid, you know, by not working. Do you enjoy not working and you know – all these kind of things and I, you know I much prefer my old life to my current life. (I: Yes, yes). And so you know and so there are certain things that I gain now and I don’t have certain pressures and responsibilities you know but there are other things that are a hell of a lot worse.

Kay: You have to come terms with it in the end, don’t you, and make a life for yourself. (Mark: Definitely)

Kerry: Yes there are certain pay-offs, I mean you get sickness benefit and that sort of thing. (Mark: Yes). Or you get extra time off. (I: Right). And time to go on holiday and that sort of thing, but there's a lot of negative things as well... (Mark: Yes) which people aren’t always aware of, they seem to think, “oh it’s alright for you you’re not working” you know it’s...

Kay: It’s harder for you cause you haven’t got (2), you can’t have the drives that they would have, can you – you know what I mean?
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Kerry: Oh maybe you have mentally but you can’t manifest it (Mark: Yeah).

Kay: Yeah, I didn’t phrase that very well, but you know what I mean.

Kerry: Yes, it’s - and it can be really frustrating especially you know when you want to get on with your life, and sort of go out to work and get a career (I: Yes). It’s always there stopping you – it’s like a brick wall in your face all the time.

Mark: It affects every aspect of your life…

Kerry: It does, doesn’t it? Yeah.

Mark: And that reflects on your self-esteem, so then sort of if professionals aren’t you know taking it seriously then – you know I’m like…

Kay: No-one else is going to are they if the doctors don’t!

Mark: No, I mean I went, I spent, I first noticed things weren’t right in the early nineties. Ninety-one I can first remember having problems like, you know, and throughout
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226 the nineties the more I played football. I’d feel awful
227 afterwards to the point where I felt I was collapsing, and then
228 so I would have a sleep straight after a match on a Sunday
229 afternoon, for about 4 hours on a Sunday afternoon. Then I
230 would get up and go to work the next day. I would feel lousy
231 for about 3 or 4 days, and then I would start to feel okay
232 again towards the end of the week and I would put myself
233 through it again. So I went to the doctor’s and they never
234 linked all the different symptoms that I had. So I would go to
235 the doctor with one problem that I then found out was a
236 symptom of ME - chronic fatigue. (I: Right). There was
237 never any kind of – it was just, oh you know take some
238 antibiotics and send you out. And then I was diagnosed by a
239 Harley Street GP who was also a Homeopath; he kind of did
240 the holistic sort of thing. He sent me for all sorts of tests and
241 made the diagnosis, but I then go back to my doctor and
242 when I see my doctor now – he just kind of looks at me and
243 it’s that thing where they are not now allowed to dismiss it.
244 (I: Right?) But they don’t want to acknowledge it either.
245 (Kay: That’s right.) They just give you that look, and it’s
246 like right okay. And the only time I got, I started working
247 again cause I had too. It was when I was married, and I’d
248 just had a son, and it was all kind of a lot of stress - and we
249 needed to get some money. So I went back to work, and then
250 – I couldn’t work any more, and I went to see an
Occupational Health Therapist by that Fire Station in [name of town]. And, erm, it was a GP who sort of went in there to help out, and she was brilliant — she kind of was the first sort of GP who had taken me seriously. (I: Yeah.) I said, “Oh can I join your — you know, can I come and join your practice…” [GP] “Oh well I can’t and I work on the other side”, and you know it’s that kind of thing. You know, you don’t want, you know don’t want to sort of con anybody, but you just want someone who takes you seriously.

I: Yes of course, and be understood. Nobody wants to go to a GP and have them look at you — and there’s lots of things as we all know that you can communicate without saying anything. (Mark: Yes, yes). And yes, being dismissed and trivialised…

Kay: They think they will throw a few anti-depressants at you, and think, “well you go away and sort it out yourself,” sort of thing. But I was lucky because, do you know [name of therapist]? (I: No.) She works with [therapist’s name] and she’s a friend of my daughter’s. Because I was down about it she said, “Have you thought about going to see, erm, whatever they’re called at [name of Hospital Department]?” (I: Yes). You know where I went to see [name of therapist]. I went to my doctor and said, “Could you refer me, because I
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have been advised to do this, and it might help me because
we’ve tried everything else.” He said, “No you can’t
possibly do that, that’s not in our remit to send you”.

I: The GP said that?

Kay: Yes. So err, I went back and, went and saw her and
said, “Look he said that.” And luckily, she being a friend of
like our family and my daughter and everything, she went
down to the doctor and said, “Look will you refer Kay to the,
not to me because I know her, and she perhaps won’t want to
talk to me, but to one of my colleagues.” So he did and that’s
the only way I could get any help

I: So that’s really marginalised isn’t it, (Mark: Hmm),
where the GP won’t even listen to you to refer you on.

Kay: Oh yes, “Can’t do that”, you know, “they don’t do
that.” And then you feel - luckily otherwise I would never
even get to see [name of therapist]. It’s still like, you had to
do it all yourself. (I: Right). There doesn’t seem to be the
help out there at the grass roots level. Once you get to
someone like [therapist’s name] and then you ring up, you
find it is really being taken seriously. But if you don’t
actually get to see someone, you think well nobody cares.
(Mark: Hmm.) Don’t you? It’s like being on an island sometimes, do you feel like that? Sort of, however you feel on the day – some days you feel a lot better than others, but sometimes you feel quite alone.

I: Yes I imagine it is very isolating to feel like that. In terms, how did your families relate to it, or the people you were with at the time?

Kay: Well at first I think, mine started that, we had worked so hard for years and years, and then one Christmas I went down with the flu. And I really wasn’t very well. And I kept getting these pains in my stomach, and they thought I had bowel cancer. (I: Right). Actually I hadn’t, but I had to go in for a big bowel operation. And I came home, and then I never got out of bed for weeks and weeks and weeks. And I just couldn’t pick up, and in the end they diagnosed fibromyalgia. But it was (2); in the meantime you think that it’s all in your head. I’d had this bowel operation and then I was supposed to then get well, in my eyes… (Mark: Mmm) and make me better, but I just wasn’t getting any better! I hadn’t actually got cancer but I’d got something wrong with my bowel anyway. So I had this huge operation, but after weeks and weeks and weeks I still wasn’t getting better, and in the end it was diagnosed as fibromyalgia.
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I: And what did your husband – was he supportive?

Kay: Oh he was marvellous! He really is supportive, but it was hard for him because he was running a pub on his own virtually, and there's me lying upstairs, sort of not moaning but sort of not being able to help. I used to cash up in bed – you know sort of do my bookwork in bed and things like that.

(I: Yes.) But once someone has diagnosed it you have got a feeling that you are not absolutely going mental. [Mark laughs]. (I: Right). Cause you do feel like that. Did you feel like that? (Kerry: Well...). “Well is it all in my mind?”

Kerry: Well I didn’t get a diagnosis until nearly 2 years after I had it. When I first saw a paediatrician just a couple of months after I got ill, he basically said, “Oh you have post-glandular fever syndrome”, and I didn’t even have glandular fever I was tested negative. I’d had flu three times and that’s why I got you know ill - I gradually got worse and worse. And he basically said, “Oh you will be fine in a few weeks and don’t worry about it.” [Laughs]. And it didn’t really sort of get any better. It did help me get extra time with my exams, but unfortunately most of my teachers didn’t believe I was ill. All my friends basically all dismissed it, saw it as me
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trying to get out of my exams and trying to get out of
schoolwork.

I: Yeah, I mean what sense do you make of it? Other than,
yes you haven’t got your arm in plaster so you others can’t
see it—so that’s one thing that people struggle to understand
when they can’t see something. But also, what sense have
you made of people responding like that? It’s almost quite
aggressive really to say to somebody, “I don’t believe you or
you’re trying to get out of something.”

Kerry: I think maybe they just see the advantages not the
disadvantages. They don’t realise, that they sort of see you
and you’re maybe okay, and then they don’t see you when
you’re at home and you’re collapsed on the bed or whatever.
They only see that you are getting out of, you know, maybe
work or schoolwork. I mean I couldn’t participate in my
lessons. I had to sit downstairs because I couldn’t climb the
stairs, and only could come in for a couple of hours a day. So
they saw me going home at lunchtimes and they just had to
go you know, and do their lessons for the afternoon so...

(Mark: Yes, they probably resented that). I could see it from
their point of view, especially as I got it, you know, when I
was sort of fifteen/sixteen, that sort of age group, they are not
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374 gonna be that understanding. They probably haven't got, you
375 know, the emotional maturity.

377 Kay: They don't understand do they?

378

379 Mark: I think – I've kind of worked in offices and there's a
culture of people, you know who pipe up, "Oh I've not had a
sick day in 5 years." (I: Right yeah.) Things like that,
"Look at me, I'm great," and you know, and it's that [gasp]
you know. I also think that this society now is, if you can't
see anything you won't, you won't believe it, you know what
I mean. (I: Right. Kerry: Yes). It's a cynical society and,
ehm, and I, I even think that, you know, about some people –
you kind of find yourself thinking, "are you putting that on?"
and you think, "no that's a terrible thing to think." But I
think that's a natural thing, if you can't see something wrong
with something, so I can understand to a degree, I mean had,
you know, I was in a sort of bad situation my family were
down in London and they were quite understanding about it.
But my wife at the time (2) was from a family, where she
used to work for her family, and she was never allowed to be
ill. (I: Right.) You know, her family would never give her
permission to be ill. At the point, at one stage (2), her mom
was shouting at her saying there was no such thing as ME or
Chronic Fatigue Syndrome. You know, and so her entire
family didn’t believe it existed, they all thought I was a malingerer, even though I was then trying to do, you know, until you try and do more to prove that you’re not and you end up doing too much. (Kay: That’s right. Kerry: Yes.) Then you end up getting ill.

Kay: Yes that’s right, it’s a vicious circle.

Mark: Yes and the stress is that.

Kay: And them saying it messes with your head. (Mark: Oh definitely!) Doesn’t it!

Kerry: You think, “Am I making it up?”

Kay: I used to think it was all in my head at one time. I used to think, if I’m in this much pain, why can’t they tell me what’s wrong with me. And you find that your friends don’t invite you out any more, because you have to cancel so often, that in the end they don’t invite you. (I: Right.) And it, it must be harder for you, because you are so young [looking at Kerry].

Kerry: Well it was hard yes.
Kay: Because you have missed time when you should be going out and letting your hair down. (Kerry: Mmm.) You know, that’s hard when you are sort of leaving school, you should be out at night going and getting drunk, and doing silly things and going on holiday with your mates and...

Kerry: Yes I think the hardest thing is watching other people and...

Kay: Do it - that’s right! (Mark: Yeah).

Kerry: They’re carrying on with their lives and going out somewhere and I keep getting held back.

Kay: Yeah! I find it when, we used to walk a lot, and we used to go out and dance, you know. And now, we go occasionally perhaps a golf club dinner with [female name] sister and her husband, and they are all up jiving and dancing and we get up and have the last dance – a slow dance. I can’t get up and jive with them, and I’m not jealous, but you just wish you could do it with them. You know what I mean? (I: Yes, yes.). It is hard, it’s like picking my grandchildren up – I can’t – the boys, my little grandson is only a year and trying to pick him up – I can’t do that. I could probably lift him up
to put him on the settee, but I couldn’t hold him in my arms
he is too heavy for me. It’s the silly things that hurt the most.

Mark: That’s what drove me, my marriage split up when my
son was six months, part of that was the stress of, you know,
the illness and how much pressure was on me to… (Kay:
Yes.) I still look after my son, ehm, probably about two and
a half days a week now, at various times when you add it all
up, and it’s great but there are still things that…

Kay: Things you miss doing with him.

Mark: Yeah. That I, you know, I can get by alright and, you
find that, you know, I can lift him up but I can’t you know, I
can’t throw him around like I used to throw my, sort of,
nephews around, you know. (I: Yes.) I’ve got a different
relationship. And of course my ex-wife met somebody very
quickly who was very physically active, and could play
football when all I was thinking was, you know, am I going
to be lying in bed while, you know, while [son’s name] has
another dad - who’s super dad, and I’m kind of you know I’m
his real dad but I’m sort of…

Kay: It knocks your self-esteem again doesn’t it!

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Mark: So that, and all that was, a very helpful part of the
process was coming in seeing [therapist’s name] and talking
about (3) Because it just happened that I went, I was booked
in to go for the ME I think I must have seen [therapist’s
name] it might have been [therapist’s name] with [therapist’s
name]. (Kay: That’s [therapist’s name].) [Therapist’s
name] rings a bell, the name [therapist’s name] rings a bell
but also I saw [therapist’s name]. I don’t know if it was at
different times, I can’t remember. And so I was booked in to
have the ME treatment, I think it was going to be Cognitive
Behaviour Therapy or whatever it, but at the time my wife
had been, you know, I was having to move out of my home.
I had nowhere to live, you know, I was miles away, I lost my
friends, cause my friends were my wife’s friends. You know,
everything went just completely crazy, and so I ended up
coming here and more or less just having, you know, more
like a counselling session and just chatting and... (I: Ehm.)
I did find it brilliantly helpful when I think. (Kay: I do.) I
don’t know what, I don’t think I would still be here if it
wasn’t for that because, just because everything was going,
you know, every area of my life, you know, was gone.

I: Yes, you experienced many losses.
Mark: Yes, yes and I didn’t know, I wouldn’t have been able to cope I don’t think otherwise.

Kerry: Yeah I had it, when I was referred, it just happened, it happened at a time when I was feeling really bad, and because I had a massive relapse after my A-levels. But I was feeling really severely depressed. I didn’t actually see [therapist’s name] first of all. I was referred, erm, I had a psychiatric nurse came round my house. (I: Okay.) Erm, that was helpful, but it was obviously she did graded exercise with me to start with. But I did feel that nothing was done in depth that, you know she did some graded exercises with me. I had to fill in diaries and things – my activities and things like that – but I never felt anything was followed through. (I: Right.) Earlier I mentioned something about CBT because it had been; they described something to me, what the treatment involved CBT and graded exercises. I said, you know, “am I going to be having CBT?”, and she said, “Well if you want it, yeah, we’ll go through with that.” And she did give me the diaries to fill in about; you know, thoughts - you know, diaries every day. (I: Right.) But she never followed through with it, and I never really had any CBT in the end [laughs].
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I: Right yes, if you are filling things in you want something to happen with it.

Mark: Yes, what's the point otherwise?

Kerry: Yes I didn't feel there was any follow through with it. And at the time, I had a lot of emotional things come up, and I didn't feel she was totally equipped to cope with it. You know, she sort of, you know, didn't really give me the support that I needed I don't feel at the time. And I did say to her, "I don't feel this is, I'm not getting anywhere with this, can I be referred to a psychologist." Because I didn't feel to be honest that she was emotionally equipped to cope with what I was talking to her about. (I: Right, right.) When I saw [therapist's name] I found that really helpful, because it was obviously more focused, and you know, it was more helpful with my problems I had at the time.

I: Do you think in regard to the CPN. Do you think the difficulty was to do with a lack of training, or do you think that was a personality thing or...

Kerry: Maybe a bit of both. (I: Right.) I didn't, I felt, yeah, it was paying lip service to the service. (Mark: Mmm. I: Sure.) And it was sort of, you know, you've got this Chronic
Fatigue Clinic, you’ve got this person coming round your house, but I didn’t feel it was getting anywhere. I felt at times she was so neutral, you know you sort of talk to her about something, and she would be so impartial that you would never really get anywhere! You know, you would be maybe asking her opinion, and she would sort of say, “If you want to do that do it and if you don’t then that’s alright.” And I think she felt so afraid of saying the wrong thing that she didn’t want to say anything at all. (I: Okay right.)

Mark: That’s quite an interesting thing, jumping in, there was quite a interesting thing I found about when I saw [therapist’s name], is that some weeks I’d go she would know to listen and (1) (I: Yes.) you know, it’s like something absolutely crazy has gone on in my life a few days beforehand, you know, because all my life was going mad in between while I was seeing her. And so some weeks I would turn up and I was in complete different headspace than other times. Then other times she would challenge me, and that was kind of, it wasn’t just, you know, it wasn’t as you say a neutral sort of passive thing. (I: Yes.) Sometimes she, she’d be, she would you know she would really push you, and it would be damn tough, and she would say, you know, “Sometimes you will leave here hating me”, she’d say, because she would try and get to the root of the issue and do
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things like that. And I thought that was good, you know, that
you felt like you was, you’d been put through, you know, you
had been made to think about things. It certainly helped me
look at, look at myself differently and change a lot of my
attitudes, and I think it helped me make me a better person
afterwards. I’ve still got ME, and I still have the same
physical problems, but mentally I deal with it in a different
way. (I: Right.)

Kay: It’s funny you said that, because I feel that I’m,
although I’m a different, I am a totally different person now
to what I used to be. But I feel in another way I am a nicer
person. It’s as if you learn, (2) it’s not humility or (1) I don’t
know what the word is even, but you are a lot more (2)

Mark: It sounds like the right word.

Kerry: It sounds like self-esteem! (Mark: Yeah but just…)

Kay: Yeah, but, but I don’t feel confident in myself even
now, but I feel as though I’m…

Mark: I think if you suffer then you can understand. (Kay:
Yeah, Yeah.) You can be more compassionate.
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Kay: Yes that's it! You're more compassion with a lot of people. But I don’t think, like when you said, there’s a lot of negativity obviously when you were talking [looks at Kerry] to her she wasn’t giving you anything. It’s as though they are frightened to give you advice.

Kerry: I think it was because she’d had bad experiences, I think she’d been blamed before. (Kay: Oh okay.) It’s like I’m going wrong – and obviously working in the sort of mental health area they’re…

Kay: They’re so frightened of being sued or whatever aren’t they!

Kerry: Yes I think that’s it! (Mark: Yes.) Yes I didn’t feel she could really cope sometimes when I was talking to her about things, I didn’t feel, she was sort of wanting to run away [laughs], do you know what I mean? And I was thinking, well if you are dealing with that every day, I think you know maybe (3)

I: It sounds like she needed some support really.

Kerry: Yeah, to me more, you know, aware and…
Kay: I know what you mean, sort of like that. It's like when I go to my doctor, and if I go sometimes (2) obviously every now and again, and I try not to be a pest, you know. [Mark: laughs]. Frank thinks I should go more often to the doctor, but when you go and they say, "Oh what can I do for you" and you say, "I would love a day without pain." Then they say, "Well you have got fibromyalgia", and that's all you get! You know, that doesn't help you, there is this negativity.

Kerry: Yes I think there is this tendency to be very, erm, what do you call it, clinical about the illness. I know they haven't, they can't obviously experience it themselves. But erm, it is very sort of, "Well chronic fatigue is this, and this, and this" [makes staccato movements with hand]. It's because, you know, it's like anyone, you know, it's just that you get more tired, and they've got very fixed ideas about what it is.

Kay: It's just like someone has written a paper that's not about real people. You know what I mean?

Mark: I don't know, you said about being a pest, but I thought that was quite an interesting thing. Cause I feel, like I go to my doctor and I think he looks at me and thinks I've got a hypochondriac here. (Kay: Yeah.) You know, because
I used to, everyone used to say, "What's wrong with you again?" because I spent years...

Kay: They do they say "Are you ill again?"

Mark: You know I spent eight active years with ME. (Kay: Yeah.) Trying to drink more coffee to get through the day. (Kay: Yeah.) Trying to take more, you know, before I did sport, I would be drinking two cans of red bull because I – just to get going (Kay: Yeah.) – I could not, you know, and all these things and then you would feel awful. When I'd go to the doctor about something and, or I'd have a headache and I'd be popping pills and people would be like, "What's wrong with you" – you know and you know – and I'd try not to go to the doctor unless I can't really avoid it.

Kay: Yes 'cause your GP is, I feel, no I find is no help to you at all.

Mark: Not on, not on the subject of ME no.

Kay: All they want to do is just repeat your prescription – that's all I go for.

Mark: Yeah that's all, yeah.
Kerry: I've been quite fortunate actually because I had a really bad GP to start with, but then I transferred to another practice and, fortunately because he had a number of patients with ME he is very understanding. (I: Right.) He has been really helpful, you know – he referred me to the Chronic Fatigue Clinic, and he found out about it for me. I mean I don’t often go to see him because I'm not a great believer in conventional medicine. (Mark: Yeah.) But he is very understanding, and I am quite lucky – but if he is not there and I have to see someone else – I get a totally different story, you know, totally different you know.

Kay: Do you think they don’t really understand us?

Probably you do [looks at investigator] because you’re looking into it, do you know what I mean? But a normal GP doesn’t understand how you feel, not in any way at all.

Kerry: Well I think it is, to be honest, it is difficult I think for anyone to understand how or what ME is like unless you know you have had it yourself. (I: Mmm.) You know I can sort of look back and think, you know, if I was that person, and you know I saw someone else with ME, would I be understanding? (Mark: Mmm.) And I maybe wouldn’t.

(Mark: Yeah.)
Kay: Yeah but your doctor's supposed to try and understand aren't they!

Kerry: Well they're human beings aren't they, they're like everyone else. I think maybe they need to read into a bit more – they tend to sort of take the...

Kay: Well I took all the papers in... (Kerry: Easy view...) That I got off the internet to my doctor and he said “Oh”, and I said, “The Government recognise it and all this and that”, and he said “Oh do they?” (Mark: Yeah.)

Kerry: I think they tend to have very closed minds on things about things.

Kay: Yes, yes like you say if you, you know, like when your dad was diagnosed with cancer, they know how to deal with that.

I: Yes well cancer is not in question is it.

Kay: No, no, this is it.
Kerry: Like I say there’s blood tests for it, it’s tangible you can see it.

Mark: But they’re - aren’t they starting to find there’s more sort of physical abnormalities with ME, or more, sort of like, is it the EPA (XXX) in the brain? That there’s lower levels of. Erm, I’ve now ended up looking up, I don’t know, this is a weird thing that’s apparently been round a while, that people with ME have less blood. Have you heard that?

I: There’s so many different theories, (Kerry: Yes.) but yeah I have heard something about blood platelets.

Mark: Yes things like that.

Kay: There’s a doctor in New Zealand who says that, now I don’t understand this altogether but, like the platelets in your blood they’re supposed to be oval aren’t they and they’re flattened out more when you’ve got fibromyalgia. So the oxygen doesn’t get to your muscles like it would do if you were normal.

Mark: But the more stuff like that is found out, the more that, you know, they can actually look and say, “You know look actually we checked…” (Kay: Yes.) Because wasn’t
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1. multiple sclerosis the same in the sixties – I remember
2. somebody saying about that. At first, they couldn’t find
3. anything wrong with people with MS. But now you hear
4. about MS and you think well that’s a serious (2). You know,
5. you could live next-door to somebody who had MS, you
6. know, and you know, what I mean. Oh she’s got a proper
7. illness and I’ve got ME, you know [laughs].

1: I think that’s it isn’t it! This thing I think in the medical
profession about, well; if we don’t understand something or
we don’t know how it starts then, you know – it can’t really
be there! (Mark: Yeah.) And that’s an arrogant attitude.

Mark: It like, it’s like you know – doctors are from a kind of
scientific, you know, they are scientists. And if scientists
can’t prove something, then you find they have very closed
minds and it’s only the best scientists the ones who actually
think outside the envelope and, you know what I mean. And
it’s like well this can’t happen because we can’t prove it and
then you think well…

Kay: That’s right, because years ago, I’m not saying my
mum because she was a nurse, but most people, the
generation before me never questioned a doctor because they
were like God. [Everyone agrees]. The Bank Manager, the
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770 doctor and the accountant and solicitor – they were all (2)
771 you know (I: Yes). You don’t question them, but now we do
772 talk to our doctors don’t we more, and we feel we’ve a right
773 to. Where our - my grandparents or people like that, if the
774 doctor said you had got two heads you had to have two heads
775 didn’t you – you know what I mean.
776
777 Mark: Also what the doctors knew to be, so okay we are
778 going to science. What doctors knew to be true a hundred
779 years ago, you know, or four hundred years ago, they were
780 treating you with leeches weren’t they - so you know
781 medicine changes and people and conditions change.
782
783 Kay: Well our perception of doctors has changed hasn’t it?
784
785 Kerry: I think sometimes though it’s because doctors were
786 out of control, because something like ME there isn’t a cut
787 and dry cure. (Mark: No, yeah there’s, no.) They can’t give
788 you a pill to cure you. They can’t give you chemotherapy or
789 insulin - and that makes them feel disempowered as well –
790 because they have got this patient and I can’t really do
791 anything.
792
793 Kay: Well yes that’s right.
I: So is that what happens in your relationship with the GP?

(Kerry and Mark: Yeah.) In that their disempowerment is projected on to you?

Mark: Yeah. Well they are going to get; they are going to get sense of failure at the end of a discussion – because they can’t help you know.

Kerry: Yes like, “Oh what can I do - I can give them anti-depressants and err.” (Mark: Yeah.)

I: Or I can choose not to believe in the existence of the illness. (Mark: Yeah, yeah. Kay and Kerry: Yes.)

Mark: If they say that, if they think that, it’s easy to say, “Well we think you’re a hypochondriac.” Then they’ve not failed, have they, because it’s like erm.

I: There’s a label – there’s a diagnosis!

Mark: Yes there’s a diagnosis, yes, yes the diagnosis is “I can’t do anything with this person they’ve invented everything.” So it’s much easier to label somebody a hypochondriac, and you know.
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Kay: I think this is why we have so much trouble with our,
our minds, about it, because the doctors make you feel that
way. You make yourself feel that way. Your friends make
you feel as though you are not like them or not like you were
because you know. (I: Right.)

II: I mean it sounds like there is a lot of stuff because you
have all talked about your relationships in different contexts
with different people and it sounds like – I feel there is
several things - and you have kind of carried on talking about
them [all laugh]. There is several things - because you have
said so much actually! I know, err, you were saying Kerry
about the fact that one of the things about a GP that you
maybe had a better relationship with, was they were
understanding. I was wondering if there were any similarities
between maybe more positive relationships with GPs or
medics, and are there any shared qualities with therapists that
you've seen. As it sounds like, I might be wrong, but it
sounds like that the therapeutic relationship you had with say
the psychologist were perhaps different to other relationships,
so I wondered what they might have been, or if that's not the
case. I don't know.

Kerry: I think the degree of empathy and understanding of
the illness, as well as, you know, the psychological
understanding of how it affects you emotionally. ‘Cause
obviously ME isn’t just a physical thing is it – it does
damage, you know, it knocks your self-esteem, it knocks
your confidence and…

Mark: I think because you get depressed from it, you then
get labelled, you know it’s like “Oh you’re just depressed”
because there are certain similarities with depression.

Kerry: Yes, I mean, I went to see one GP and said, I was
really seriously depressed and she basically laughed in my
face. She, you know, thought I was, you know, trying to get
a sick medical certificate or something for it through it. (I:
Right.) I think there was a bit of err, controversy I think over
ME, and they tend to think “Is it depression that causes the
ME or is it the ME that causes the depression.”

I: As Mark said, there are a lot of symptoms that mirror each
other, so it gets this diagnosis of depression as well.

Mark: ‘Cause I spent ages training harder to try and get
fitter. (I: Yeah.) And thinking “Well, hang on a minute why
am I feeling ten times worse” – I went through that stage of
denial – which I read about as in Dr Shepherd’s book, you
“know, on ME. And he’d said that he went through the stage
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of going for runs to try and beat it, and I did that, I did all that
and just ended up getting worse and you know. But the
depressing thing is I knew that I wasn’t depressed when I was
- you know, I got ill during, you know, when my life was
going swimmingly. And you know, and it was only
afterwards that I then got gradually got depressed, and
realised that I got seriously depressed. But I kept, you know,
I kept sort of denying to myself that I was depressed –if that
makes sense, because I didn’t want to be labelled as
depressed. (I: Yes.) Because I knew that wasn’t, you know,
but obviously if your life’s, if everything in your life goes,
you know, is turned upside down and turns pear-shaped
you’re gonna be depressed. Anyone with an illness would be
depressed.

Kay: And when you say you’ve got depression that
sometimes, with some people, brings out another stigma
doesn’t it?

Mark: Well yeah. It’s again, how can you prove that you’re
depressed, how can you see…

Kay: That’s right, you know, I’ve got a sister-in-law that
says she’s never ill, [corrects self] never well, but there’s
nothing really wrong with her. She can shop seven days a
week, (Mark: Yeah.) go out for lunch and goes out ever such
a lot. And when I said to her I was going to see [therapist’s
name], she said, "Oh where are you going to see her?" And I
said, "at the [name of Psychiatric Liaison Ward]." She said,
"Ooh, you ought to be careful there, that’s where all the
nutters are." [Mark laughs]. And you think, "That’s another
one." You know, another negativity. (I: Mmm.) And in the
end you don’t tell people where you’re going.

Kerry: There is a bit of a stigma attached to it.

Kay: Yeah. ‘Cause [therapist’s name] did say to me, what
did you feel like when you walked into the [name of
Psychiatric Liaison Ward] and it’s written across the door
“Mental Health Unit” or whatever and at first. Frank came
with me the first time and I thought, “Ooh”, it wasn’t a bad
ing thing, but you thought, “am I in the right place for what I
need?” (I: Yes.) But I was.

Mark: I try not to think, don’t know, I don’t like, the,
depression and mental illness – you think of mental illness
and you think of sort of I don’t know...

II: Some severe mental illness?
Mark: Yeah, you think that's slightly – you know depression can be severe if you have it bad enough, but, it’s, as you say you, think of more insanity rather than you know...

Kay: Depression and anxiety. Yes I used to have anxiety attacks.

[One member of group stops the discussion to go to toilet. Facilitator suggests a break]

Kerry: I think on the side of depression there is the tendency to focus on what you can't do, more than what you can do.

Mark: The best thing is to concentrate on what you can still do – if you go down the route of what you can’t do you (2) you know.

I: But it almost seems, from what you are saying, that you have to go down the route of what you can’t do to get to that position of focusing on what you can do.

[All agree]

Kay: It doesn’t happen over night, it happens over a series of years doesn’t it? [All agree]. I was really upset because I’m football mad. And I thought, "Well I shall never get to see a
live game again. I'll be watching it on the telly.” But we've
found a bus, we go to [name of neighbouring city], I
shouldn't say this really in [name of city] but we go to [name
of neighbouring city] to a pub. We go on a bus to right
outside the stadium, and back on it again – so we found a
way to go to the football.

Mark: ‘Cause I was, as I say, I mean, when I gave up really
gave up playing semi-professionally - one of the reasons was
I was starting to feel ill, but I didn’t know anything was
wrong with me, but I was at the time I was driving up to
[name of a northern English city] to watch [name of a
northern English city] play, I was a season ticket holder at
[name of a northern English city]. And then that was until 3
years ago that was, I was still a ticket holder but I didn’t have
the money. Then the journey was too long for me to drive
and come back and I would be exhausted if I did do it, and
you know, I had to give up a lot of things and that kind of
phased out over time. And then you start thinking, “You
know I can’t play football but I can still go to football.”

(Kay: That’s right.) I used to have friends who would drive
up from [name of a southern English city], and they’d pick
me up, but then, but that dropped out…

Kay: See you do find a way of it don’t you.
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Mark: Yeah, but there's certain things like if I go out, I go out for a quiet...

Kay: I can't go to away games. (Mark: No.) Because I don't know whether I will be able to get near enough to a stadium to get there. Because it drops you off right outside the gate where I go in.

Mark: Yes that makes it...

Kay: And it's wonderful, you know. And I don't go every week because I don't always feel well enough to go. (Mark: No.) But then one of our relations in [name of neighbouring city] will take my ticket, which is great!

Mark: Yes it's tempting. I mean I still go out. You know a lot of evenings I won't feel like going out. But I still lead a pretty, you know when I'm at my worst, yeah you know, I've never been so bad that I'm bed-bound - I can always kind of get about. But there's, you know, I have times when I find it hard, in the evening I feel pretty poor but you know, I can go out once a week, you know, but I can't go night clubbing, I can't drink, you know if I drink I get ill...
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Kay: I can’t take me tablets if I drink…

Mark: So, there’s all sorts of different things…

Kay: So I’m the driver now you see, which is great for everyone else, isn’t it, so yeah you’re not that useless are you.

[All laugh]

I: Great for everyone else but not for me! (Kay: I don’t mind.)

Mark: It’s nice to have a use I suppose, at least you feel useful.

I: So you have got a role? (Mark & Kay: Yeah.)

Kay: Yeah, they all have a drink, we go quizzing on a Thursday night. And I can sit and do a quiz so that’s something I would never have dreamt of doing years ago but I enjoy it.

Kerry: But like you say it is really tough on your social life.

(Mark: Yeah.) Because I basically have a very limited social life because I can’t sort of go out in the evenings and go out drinking.
Mark: Yeah. Have you not got any friends that can take you, you know, that you can find things to do that...

Kerry: Yeah. I was going to say, I have found things to do, I mean I have started doing some voluntary work. (I: Right.) With young people and, and I go out with friends in the daytime if I can. They tend to drive me, you know, somewhere so that I don’t have to walk very far. Yes you do that and you have to sort of make compromises. (Mark: Yeah.) So you go out for an hour instead of three.

Kay: That’s it. When I get home from the football I get on — Frank’s bought me a recliner chair, and I get on that with the remote control turn the telly on and I’m asleep, you know. You sleep through the evening because you’ve been out in the afternoon. (I: Mmm.) It’s like driving, I don’t feel confident enough to drive — this is the furthest I’ve driven for a long time.

Kerry: I can’t drive any more than about three or four miles at a time without getting too tired so, I tend to, you know. I do drive into [name of Town] which is only just up the road, but I can’t drive any distance, so you know it’s really difficult to get anywhere you know.
Mark: Your life kind of shrinks down in that sense doesn’t it? Everything gets more local and that can be quite, I know, I got my own car now but when I was with my wife we had one car and she was out working and she’d have the car. So I’d be stuck at home all day and if I wanted to go out anywhere I would have to walk. (I: Right.) Then that was waste… (Kay: And you can’t…) Well yes I can still walk a mile a day not too bad. Anything above that, and I’m you know I used to be, when I was first diagnosed – because I had been playing football up to the point I was diagnosed – I used to have do 4 or 5 miles walks and that would be shattering.

Kay: The one thing that [name of therapist] was really helpful with – she said, “Why are you worried what’s gonna happen?” and I’d say, “Well I don’t (2) nothing I suppose really.” But you think “Supposing I can’t get back to the car and I don’t feel very well”, and you think…

Mark: The thing is not being in control of your own energy.

Kay: That’s right! That’s what it is! Yes it’s the control isn’t it?
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1068 I: Yes something that strikes me really overall, I mean at the 
1069 beginning you were saying - and actually this is mirrored a 
1070 lot by what people were saying in the other groups as well - it 
1071 seems to be a common experience that when you’re reflecting 
1072 back of how it all started you are all pretty high achievers, 
1073 you are all motivated and doing a lot - you had exams 
1074 [looking at Kerry] and all the training and a job [looking at 
1075 Mark]. And you know everybody knows that being a 
1076 landlady is a 24/7 occupation [looking at Kay]. So there is all 
1077 that going on and I imagine, I suppose I’m making a bit of a 
1078 leap as well, but something strikes me that people seem to be 
1079 perfectionists (Mark: Yes.) as well about what they do. 
1080 (Kay and Kerry agree.)

1081

1082 Mark: [name of therapist] used to say, “You are so tough on 
1083 yourself.” (Kerry agrees.) Well I am, and you know, about 
1084 everything I do.

1085

1086 Kay: You want what you do to be right.

1087

1088 Mark: Yeah! And it’s, you know that’s all, perhaps all part 
1089 of the stress you put on yourself, and I think stress, (Kay: 
1090 yeah it’s important.) stress and pressure does make you feel 
1091 worse.

1092
Kerry: Like what you was saying earlier about not being able to accept your illness. (Mark: yeah.)

I: That's what I was thinking, how does that fit in?

Kerry: I totally, even now, I constantly over reach my capabilities. I take on too much. (Kay: yeah.) I take on other commitments, I've taken on a new course and doing voluntary work and it's like my mind can do it all but my body can't keep up. (Mark: yeah.) And you're...

Kay: But you've got to have goals haven't you, otherwise, like Frank will come home some days and say, "What have you done?" And I like my house to look nice and you think some days to even take the Hoover from under the stairs, (Mark: ehm.) you can't do it. And then another day, when you're feeling good, you sort of, you want to do the whole house from top to bottom. And then he comes home and says, "Well you've done too much today", but if you didn't do too much I think you'd give in - do you know what I mean? (Mark: I do.)

I: So to challenge yourself - but there has to be a balance.
Kerry: Yeah, I don't know. I think it's maybe you know setting your limits a bit lower and setting the goals to be attainable rather than out of your reach, because I know the people that have got better have just focused on getting better in themselves, and their health rather than external things. (I:
Right. Mark: Yeah.)

I: Yes cause I mean, going back to what I said a bit earlier about being high achievers and being busy and all the rest of it I mean there's something about having a lot of control as well [Mark and Kerry agree.] with that. Then CFS comes along, and takes control and you know, and it's like you have a relationship from what you are saying with your CFS or ME. But this thing has come and in some ways you know especially what you were saying Mark, it's robbed you of lots of things, [Mark agrees.] of lots of things, of your marriage, you know, of being with your son of all these things. And Kay, not being with your grandchildren the way you would want to be and your grandchildren [Kay agrees]. I was wondering about that, I mean have you ever thought of it in terms of a relationship? 'Cause it seems like when it is by the way you talk about ME, it is separate from yourself - is this making any sense?
Kerry: I don’t know, I think sometimes you can tend to think the ME takes over your life so much you tend to think, “Oh am I the ME?” do you know what I mean? (I: Right.) I said that to someone, “Am I the ME?” (Laughter). ‘Cause it’s so much part of my life, you know what I mean, it’s constantly there - and I want to do something oh god you know you can’t do it.

Kay: Do you think it’s frightening that it’s constantly there sometimes?

Kerry: Erm, I mean it’s not so bad as it used to be, but you tend to adapt better as you have it longer. But I think it is, it does, it can have a tendency to take over you and your personality, your identity even - because you know with the ME and as the symptoms are you get brain fog, fatigue…

Mark: That was the point I was going to say earlier about getting tired though, you know as I say physically tired. When you were saying about doing an OU course and all these sort of things it’s – it’s how mentally tiring things are and, you know, as you say the brain fogs and the headaches and all that kind of stuff that doesn’t, you know it’s not just, perhaps so commonly acknowledged. But that even makes,
you know, if just walking around that was tough and well you
could just sit there and you know…

I: Yes – so there’s the cognitive effect. (All agree.)

Kerry: I find the fatigue is the worst. I mean I could
manage if it was just muscle pains, and not being able to walk
around I’ve adapted to that – it’s the fatigue that limits me
from doing things. Mostly because I just get so exhausted I
just have to lie down all the afternoon, and you know, you
have to have regular rest whatever – but it’s that – I think
that’s the main symptom for me anyway apart from anything
else. (I: Yes.) ‘Cause obviously the pain, pain is hard to
cope with but you can take painkillers. Fatigue, you know,
there’s nothing that eases it.

Mark: When I’m feeling like that and I have a coffee it just
makes me feel ill. You know, when I’m feeling okay and I
have a coffee gives me a little boost. If I’m feeling bad a
coffee is just gonna make me feel – you know, it just makes
you feel worse. It’s a strange thing it might make you more
alert but it just makes you more aware of feeling rubbish in a
way. (Kay: That’s right). It’s just I mean the point you are
making (I) about the ehm, (2) the ehm [huffs] I’ve lost my
train of thought (2).
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I: Well I’m trying to think about what point I made.

[Everyone laughs.]

Kerry: It’s a memory loss. (Mark: Oh deary me!)

Kay: That’s how I am. They all think I’m daft at home – my daughter and my husband and they say, “Oh she’s gone again.”

I: I’m talking about having a relationship…

Mark: With the, oh yes. It’s how hard you are on yourself and how, you know, I think I have accepted now that I’ve got the condition. I’ve finally got to a stage where you know I don’t expect to get better, you know, I think that’s important thing to come, you know – I hope to get better.

Kay: Yes come to terms with it.

Mark: Yes but it’s that thing, you know, I don’t want to wake up every day thinking, you know, today’s the day I get better and then you know by ten o’clock…

Kay: You get the disappointment.
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Mark: Yes I’ve accepted that, and I’ve accepted that I may
never play football again, and that you know, was hard. I’ve
accepted, you know, I think that over a period of time you do
adapt you know – giving things up straight away is hard.

Kay: You have to otherwise you’d crack wouldn’t you?

Mark: Yes, but I still, you know, I’m still you know, I have
a lot of things I enjoy in my life.

Kay: You try new things don’t you?

Mark: Yes, but I’m saying but that’s the point I’m finding
new challenges, new things. (I: Yes.) You know, I’m
writing a book. I got into, when I thought I was still well, I
got into internet-based football writing. (I: Right.) That lead
to sort of, quite a lot, you know I write quite a lot on the
internet – quite a large following. (I: Fantastic.) People said
just write a book – I’m writing a book… (Kay: That’s
fantastic.) So I’ve written nearly finished writing a book,
ehm I’ve already got 500 pre-orders for it to sell.

Kay: You wouldn’t have done that before though would
you?
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1240

1241 Mark: See no I wouldn’t of done that, and I think about that, and think that someone could say, “Wow”, (2) but I would
1242 still rather be playing football than writing about it. But you
1243 make the best of it! But now I’ve set my, but now I’m
1244 thinking, “Oh alright”, you know, I’ve now set myself under
1245 pressure because it’s sort of time-sensitive. It needs to come
1246 out this summer, it’s nearly finished, but then you start
1247 thinking, “Am I doing too much?” Then it’s the whole thing of, well if I make a little bit of money out of it, will it just end
1248 up that I lose my benefits? (I: Okay.) And then I end up
1249 actually worse off. You know I have to borrow money off
1250 my parents to get by, because my housing benefit doesn’t
1251 cover my rent or anywhere near. I mean I get incapacity
1252 benefit but that doesn’t – and it’s also the thing that people
1253 will then say, “Well if you are well enough to write a book!”
1254 But then I can – my day is completely my own [Kerry and
1255 Kay agree.] If I write for an hour then, you know, I can feel
1256 rubbish for 3 hours or feel rubbish for the entire day. I don’t
1257 have to do anything, the hardest thing is…
1258
1259 Kay: The pressure’s off you isn’t it? (Mark: Yes, yes.)
1260 That’s how I feel because I’m not at work I haven’t got that
1261 ultimate pressure of saying you’ve got to get up dressed and
1262 get out the door for nine or whatever – my day was back to
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front to everyone else's, but if I'd have had a normal job. But
now I mean I always make sure I'm dressed for say ten
o'clock, and I won't go to bed in the day — but I've got a
recliner chair so it's that it's better for me to get in the chair.

Mark: I've got to that stage as well.

Kay: So I watch the telly or read if I can, I can't always
concentrate but I make sure I will not let myself be in my
dressing gown all day, you have to don't you?

Mark: That's, that's a big thing. [All agree.] I mean I set
my alarm in the morning, and I used to sleep during the day
when I felt rubbish, but then it affects my sleep at night. [All
agree].

Kay: 'Cause I still have nights when...

Hi: It's all management isn't it.

Kerry: I just tend to lie down. I don't go to sleep I just lay
down and rest [Mark and Kay agree] instead of sleeping.

Kay: That right it's like resting your body isn't it? [Mark
and Kerry agree.] But I can still have, but not so bad now, at
one time I would be up two or three nights a week. Now it’s
once or perhaps two times a month, but I still make myself
get up and get dressed in, you know. I get in the chair in the
night, and watch the all-night telly, which is a blessing
[laughter] that it’s on. Do you know what I mean? ‘Cause
your mind won’t go to sleep, and you’re in so much pain and
then you sit in the chair, but even then in the morning I won’t
go to bed – I make myself go and have a shower and get
dressed. (I: Right.) Otherwise…

I: So you are keeping those - your own standards?

Kay: You’ve got to haven’t you? Otherwise you become a, I
don’t mean a couch potato as such, but you know what I
mean.

I: Yes, yeah I do know what you mean.

Kay: You would live every day in your dressing gown and
never comb your hair (2). You’ve got low esteem anyway,
you don’t want to go any lower do you know what I mean –
you’ve got to find a level that you won’t go under.

I: So it seems as well…
II: Sorry to interrupt (I) it's half two now so it's just gone over an hour.

I: Alright thank you very much. Is everyone okay to carry on a little while longer? [All agree.] Say 15 minutes? [All agree.] Sorry I know that some of you have someone waiting [directed at Kerry]. I was thinking that the characteristics of people that have ME/CFS, I mean these things are generalised really and it doesn't count for everybody, but it seems like these qualities that you have you need them to manage the CFS. It's almost like you need to have some control in a way, over how you work your day-to-day life and how you manage your life.

Mark: Routine, routine is definitely important. (Kay: Yes definitely).

Kerry: I don't think you maybe have those qualities or maybe don't have those qualities developed to start with, I think maybe they develop as you progress with the ME. [Mark and Kay agree.]

I: Yes certainly it does sound like a process.
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Kerry: I certainly didn’t have any self-control over my ME
(laughter) as some will say. (Mark: No, no.)

Kay: So in the end you have to otherwise you...

Kerry: You do don’t you? (Mark: Definitely.) It certainly
developed with me anyway.

Kay: [Name of therapist] helped me plan my day, half hour,
half hour, half hour – work half an hour, rest half an hour,
work half an hour, and rest half an hour. You sort of ... you
can’t do that sort of every day all day - but it does help
sometimes to say look well instead of working for an hour
and being absolutely shattered, work for half an hour sit and
perhaps have a coffee or sit and read the paper.

Kerry: I think it depends on the person because I’m very
much a person of extremes I tend to go over what I can do...

Kay: Well I am but...

Kerry: And do a lot and I can’t, I can’t have a restricted plan
or that model. I mean I did when I first got referred to the
chronic fatigue clinic – you know the psychiatric nurse said
to me, “well you do this and you pace yourself like this”. I
did that, and to be honest it made me a lot more depressed
than I was to start with... (I: Right.)

Kay: I can't do that all the time.

Kerry: It's so restrictive and I was thinking, "God is that
what I'm doing each day? I'm doing the same thing each day
am I going to increase it by 5 minutes - 'is that all my life has
resorted to'" (Mark: Mmm.)

Kay: She just sort of taught me to sort of not do more than
half an hour...

Kerry: I mean there is two sides to the coin but...

Kay: But you do, when you feel like well and want to
hoover for an hour you do - you know what I mean.

Kerry: Yes I can see that.

II: It's something I think, well I don't know what (I) will
think of this, but the last group as well I think we were
talking about everything was very individual. And I suppose
like the whole thing about how therapeutic things that are
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given almost as, you know, I suppose as a health professional
you are given your package aren’t you, like the GP…

Mark: Yeah (in agreement).

Kerry: Yeah. It’s not gonna work for everyone is it?

Mark: It needs to be adapted to peoples’ particular situation.

II: But yes you need to broach that with people, and get
them to try some of it, but it’s very individual, so what works
for some people may not work for somebody else...

Kerry: Yeah, I think that’s the same with any sort of
therapy, or alternative therapy because people have said to
me, “Oh this tablet’s cured me, this homeopathy has helped
me”, and I don’t know about anyone else but I’ve pursued
every single… (Mark: Yeah. Kay: I have.)

Mark: Yeah I’m quite cynical about that ‘cause it’s
something like, you know, you’ll get like, “I’ve cured myself
of ME by doing this!” (Kerry: Yeah.) You know, and you
think you know well a, you might have been getting better
anyway; b, that might have worked for you, you know it is an
individual thing. [Kay and Kerry agree.] You know I’ve tried lots of different things.

Kerry: Yeah, I’ve had about thirty or forty different therapies…

Mark: Yeah, a lot of people have. You know, you’ve got to, sort of, as I say, cause a lot of people do, it is cyclical, a lot of people do get better, a lot of people get better (2) then people say they’re cured of it and they might get it in five years time! (Kay: Yeah that’s right.) I know people who have had it, lost it and then it’s come back…

Kay: It’s like being in remission isn’t it. (Mark: Yeah.)

II: Can I just ask, thinking about the different therapies, do you think - in terms of things that were helpful and things that weren’t, going back to this idea about relationships, do you see any, when you reflect back on it now, was part of it about your relationship with somebody?

Mark: What as in the treatment?
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II: Yeah, because I know that when you were talking about seeing [name of therapist], it sounds like that was different to other relationships...

Kerry: I mean, yeah I found that particular Chronic Fatigue Clinic was err, I mean [name of therapist], I did find that very beneficial in terms of helping me to communicate. You know, and proving communication in confidence with talking about my illness, you know, that sort of thing. But I did find that it tended to go round and round. Erm, how to explain it?

II: Is that with [name of therapist]?

Kerry: Yeah. I did find that I didn’t get any resolution sometimes to my problems. I know there obviously isn’t a clear resolution always, but erm, I didn’t find that, erm, I found it sometimes going round in circles, do you know what I mean? And that maybe something that was more solution-focused, you know, or goal-setting, that sort of thing would have been more beneficial.

Kay: Do you think there is a solution?

Kerry: No, no I don’t mean a solution to the illness, I mean maybe you come with certain erm issues, to erm therapy.
And maybe having some goals would (2), you know, in terms of recovery, would have been more beneficial, you know, in addition to that, and maybe helping with self-esteem, 'cause I didn't really think that anyone really covered that. 'Cause I think that is quite a big issue with the illness. (Mark: Definitely.) Improving self-esteem and self confidence will help you, you know, whether you are still ill or you're starting to recover. Because it is one of the major things I think, you know, with the illness and part of getting better as well. (I: Right.)

Mark: It doesn't mean that you have had to have had sort of low self-esteem before hand. (Kerry: No.) I mean once you have got the illness your self-esteem does reduce, drop...

(Kerry: Take a knock...) I think that is erm, I don't know if there is, if there are any group sessions? I mean I've found it quite helpful to sort of come in and chat about it. One thing is there's an Internet forum that you know I've kind of contributed to, and I pop on that every now and again. Erm, for sort of people in their twenties and thirties, and I think you know erm, that's been pretty helpful for me to discuss things with. You know it is nice to discuss it with people, and I don't know if there are any other groups? And I phoned up one ME group and, the (name of city and name of group), they've become some splinter faction from the one
ME group, cause you know all the ME groups were getting political and…

Kay: That’s like, that’s how the Fibromylgia Society got.

(Mark: Yeah.) And I used to get a newsletter every month.

(Mark: Hmm.) And then the National one wanted to take over the [name of city] one (Mark: Right, laughs), but I’ve never gone - actually to it.

Mark: No, but it’s nice if you…

Kay: But the newsletter was quite helpful to receive. But I had, I had this idea in my head, I said to you, it was like there would be all old people rattling round the table XXX [laughs], you know what I mean? The chap that I spoke to, the secretary, his wife has ME, erm, fibromylgia, and he sort of is the secretary of the group. And he was on for ages and ages, and it was just like, I came off there and I was that depressed [Kerry and Mark laugh], when I was talking to him, I thought [all laugh] if I felt like that then, what am I going to be like if I go to the group. So I never went!

Kerry: Yeah, some of them can be really negative, I went to one (Kay: Yeah), all that they basically did was sit there and wallow in it!
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Mark: Oh yeah, I had thought about that, yeah!

Kay: And I didn’t want to do that...

Kerry: It was like it was their major hobby, part of their occupation in life was to sit there moaning about it!

I: But I guess it’s...

Kay: It might help them, I don’t know!

Mark: It’s nice to moan as well. (I: Yeah [all laugh].) If it’s the only time you get when everybody else takes you seriously then...

I: Well I was thinking that perhaps what might help them is that others can relate to it, so it’s a common experience.

(Mark: Yeah.)

Kerry: Yes it is good to share common experiences, but I think, my mum went there actually to do a talk, she’s a therapist, an holistic therapist - she did a talk on ME and therapies. And she said none of them were interested in
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1534 really, you know, approaching anything or trying anything new.

1537 **I:** I guess it depends on what stage you're at, I mean if it's an early diagnosis…

1540 **Kerry:** I think some of them - they’d had it quite a long time and they were prepared to sort of, just live with it.

1543 **Mark:** Or maybe they’d tried everything…

1545 **Kerry:** Mmmm, I don’t know but…

1547 **I:** Okay, I understand what you are saying…

1549 **Kerry:** You know what I mean. It was quite, sort of…

1551 **I:** And I think a lot of people are open to exploitation as well…

1554 **Kerry:** Oh yeah, well there’s desperation isn’t there, of getting better. [All agree.] I remember seeing therapists charging very extortionate prices. I’ve tried this new thing, I don’t know if anyone’s heard of it, reverse therapy. There’s been quite a lot of, well there’s been a bit of press about it
but, I actually tried that after I got, you know, I stopped seeing [name of therapist], and err, 'cause a number of the people said that it cured them. *(Mark: Right.)* That it's this new cure for ME. *(Mark: Mmm.)* Erm, and it has helped a friend of mine, it's helped her quite a lot, she was really severe, but it didn't help me unfortunately and it was sort of eighty pounds a session. *(Mark: Yeah).* So it's quite, it's quite, you know, I'd built up my hopes to think "this was the cure, this was the one thing that's gonna do it", and it didn't.

I: Do you think that therapy helps you and the ME, or does it help you, and the ME stays the same? *(Kerry: Erm.).* Do you know what I mean?

*Mark:* I think that the better, the better you...

*Kerry:* Well it builds up hope. I think it gives you hope, 'cause there is that feeling of, you know, of desperation, that "Oh I'm going to get better. Or am I ever going to get better?"

*Mark:* I think that if things help you, then the ME can be helped as a result of that.

I: A knock-on effect?
Mark: A knock-on. But you know, the better I feel in
myself mentally, I might still feel rubbish physically, but but
you don't you don't think "Oh I'm just gonna, I'm gonna..."
You can still perhaps motivate yourself. And I think, I know
that if I went out, I can have days where I feel fine, and I
know from the past, you know I could go out and do
something I didn't think I could do, but then you pay the
price.

Kay: Yeah, yeah, that's right

Mark: You know, erm, I think if you feel good and you
know, if you push yourself too far but you don't go too far,
you know, then, you can kind of manage it and you have your
ups and downs...

Kay: I think you do have to push yourself a bit though.

(Mark: Yeah.) Otherwise you become (2) well...

Mark: I think, I think I'd find like graded, erm graded? (I:
Graded exercise?) Yeah graded exercise, stuff like that I'd
find really hard to do cause days where I have my son, you
know, he's a three year old, you know, he's not going to
understand the concept of ME. [All laugh.] He’s like
“Daddy do this now.” So...

Kerry: And sometimes pacing regimes can cut out all the
fun out of your life, and sort of days, the days where you sort
of, maybe want to do something that is a bit mad,
spontaneous…

II: Yeah, I was gonna say, it takes away the spontaneity if
everything’s planned. (Mark: Yeah.)

Kerry: And I found that life’s so bloody miserable at times,
that I didn’t really want to…

Mark: Well it’s nice to have a routine but it’s nice to be able
to scrap the routine, and have some flexibility.

I: So it sounds like it needs to be realistic.

Mark: Yeah. And you don’t want your hopes built up and
anything as well. So, with any kind of treatment, if you are
going through feeling, I mean when I was diagnosed the guy,
you know, was getting me a list of things to take for the first
month, and it came to nine hundred pounds. Now, after, in
the end I did about six months, you know - without paying
for everything on that - but it was probably about three hundred pounds per month. And then when I realised, I felt better in myself, (I: Right.) as I was on a complete detox diet, and err, usually I felt better, and then you get cravings for things back, and then when I realised it wasn’t going to cure me. Then it’s very hard to, you know, to be on a seaweed diet or something, you know, if you know it is not going to make you better in the long-term. And you can do it if you think it’s going to. Then after that you come down because you’re not better, do you know what I mean? So you’ve got to kind of be open-minded but not have your hopes raised, you know.

Kerry: Yeah, it’s about being realistic about what the effects are going to be.

I: So it’s about balance again? [Mark and Kerry agree.]

Kay: You’ve got to be quite strong minded I think. I used to go home from seeing [name of therapist] and be absolutely exhausted. And I’d only sat talking to her, but it was just like, relief’s not quite the word, of being able to explain to someone that I felt understood. Because you can talk ‘til you’re blue in the face to somebody else and they’ll just look at you as if you’re a zombie. Do you know what I mean?
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II: Yes. I was just wondering really, you’ve all said a lot about different relationships in your life, but if you reflect on different relationships in your life - generally as a whole, including professional and personal ones, do you see some relationships mirrored in others?

Kerry: Yeah I think, as I was saying earlier the empathy, you know, and the understanding.

II: Did you find some of that in personal relationships as well?

Kerry: I think, certainly with my parents, I mean after a couple of years, I think at first, there always was, you know, disbelief. (Mark: Mmm.) But I think as they see you with the illness, and as you progress with the illness, I think they can, sort of, get that understanding and sort of empathy...

Kay: It’s hard for them isn’t it?

Kerry: It is hard, it is hard.

Kay: I think if I was your mum, I would be desperate to help you.
Kerry: Yeah, especially as she’s a therapist. [All agree.]

She was very much about “Oh I am going to cure you”, sort of thing, and that was her project…

Kay: I am lucky ‘cause Frank is marvellous. He does the ironing and things I can’t do. And…

I: Yes it sounds like Frank really understands your experience.

Kay: Yeah, yeah. He’ll say something some days, and you think (2) “But, I thought you understood.” But they can’t understand hundred per cent.

Mark: Not a hundred per cent, no.

Kay: But he does his best. And your parents obviously do, ‘cause it’s good for you to have that err, unit that does help. I’m lucky that my daughter’s good and my son-in-law’s good. You know, and my grandchildren know that (1) I can’t do what his other nanna does. (Mark: Yeah.) I mean they bike from…

Kerry: It’s having a support system…
Kay: from [name of town] to [name of city] on a tandem. [I and Mark laugh.] You know, I couldn’t do that when I was well. [All laugh].

I: What do you think Mark to IP’s point about relationships, in that can you see any relationships in your life mirrored in what you had therapeutically?

Mark: Ermm, erm, my mum was pretty good about, you know, she’ll get things out the paper, and I believe that my mum believes me. [I: Right.] I kind of half believe that my dad does but he’s seventy-five, he doesn’t really understand, you know what I mean, but you know he’s got a lot better now, I think he takes me seriously, for years he thought I was just a lazy git really. Ermm…

Kay: That’s hard isn’t it?

Mark: Yeah. And my friends, I haven’t got any friends that would even talk to me about it, or ask me about it - no friend has asked me how I am…

Kay: No, erm, no, people don’t. (Mark: They ask me…) What they just say is “You look well, you look great today.”
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1733

1734 **Mark**: If I talk to somebody about it they don’t, there’s kind
of a bit of a silence. And I’ve made friends, you know,
basically from the Internet who’ve got ME. And so then...

1737

1738 **Kerry**: All my friends have got ME actually!

1739

1740 **Mark**: Yeah [laughs] so, so...

1741

1742 **Kerry**: Sounds sad, [Mark laughs] but it’s that
understanding...

1744

1745 **Mark**: Yeah, you know...

1746

1747 **Kay**: I’m lucky, see I don’t have that. (Mark: Mmm). But
then I don’t have a big circle of friends, since we left the pub,
my life’s pretty much at home, and, with my daughter and
Frank...

1751

1752 **Kerry**: Yeah, I think you do find that you have fewer
friends. But, mainly better… (Kay: Yes better friends.)
Better quality friends, and quality relationships.

1755

1756 **Kay**: But people that I was sort of, when I was in the pub
and we had a night out, you know, a night off, and we’d go
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out with, all of them have gone (2). But things like my son-
in-law’s mum and dad we’re, we’re all like a close extended
family now. And, but, as, I’ve one friend who’s seventy-five,
so she keeps up with me and I keep up with her. [Mark
laughs with Kay.] It’s silly really but you do find your circle
of friends shrinks.

Mark: I think if you’ve got just purely social friends, they’ll,
they’ll go. (Kay: Yeah they go.) [Kerry agrees]. Well they
are not like proper friends. All my friends are dotted all over,
I’ve not got many friends here, cause I’m from XXX, and
then from university I’ve got friends there, but you know
everyone’s, but you know, that’s the great thing of, you
know, without the internet and email I think I’d go mad,
’cause I can keep in touch with everybody.

Kay: Still have a few social friends as such, but not the
social friends that say “Ooh I’ll meet you next week and
we’ll go to so and so”. You can’t be that spontaneous. You
have to sort of wait ’til the day and then you ring up and say,
“I’m sorry we’re not coming”, because Frank wouldn’t go
without me. You know, and in the end people stop inviting
you. (I: Right). And that’s quite hard. So in the end you
don’t do what you did do…
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1783  I: Right. I'm just aware of the time.

1784

1785  Kay: Yes that's right.

1786

1787  Mark: [Laughs] You're just not taking us seriously are you.

1788  [In a mock stern manner - everyone laughs.]

1789

1790  I: Can I just ask, briefly, is there anything burning that you

1791  wanted to say that you haven't had the opportunity to say?

1792

1793  Mark: I've only got really good feelings from my time here.

1794  Erhm, so...

1795

1796  Kay: I've found, I've really enjoyed this afternoon (Mark:

1797  Yeah.) because I've never sat in a group and talked. And it's

1798  nice, especially as you're both being younger, and I don't feel

1799  as though I'm an oddity. Do you know what I mean? To

1800  listen to you, it sort of mirrors, in different ways obviously,

1801  'cause you're a different age group, but the same feelings,

1802  (Mark: Mmm,) it is nice to know that I'm (2)

1803

1804  Mark: That you're not alone. (Kay: Yes yes.) GPs know,

1805  but I mean like [name of therapist] and that were absolutely

1806  fabulous, she was marvellous to me, I wouldn't even go into
town, or go out on my own or anything! And I drove here

today on my own.

I: Good, so things have really moved on for you.

Kay: Yeah, you just make your life different!

Mark: Yeah. I'm in a better place than when I first came here. Perhaps I would have been anyway, 'cause you rebuild your life anyway...

Kay: I feel better than I did in my head a year ago. Not in my body but in my head. And that helps you to carry on doesn’t it? (Mark: Yeah.) I, you can see the wood for the trees sort of thing.

I: Certainly. Kerry did you want to add anything?

Kerry: I don’t think so. Like you say, I think it has been valuable - definitely, you know, to speak about your experiences.

I: Right, I'm glad you have all got something out of it, I certainly have.
Focus Group 3: 19th March 2005 at 2.00pm.
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Kay: Are you doing this for the university? Is it like a university course that you’re doing?

I: Yes I’m at Leicester University.

Mark: Sorry. Do you have friends, do you, have you got any ME groups on the Internet that you’re (2) [directed at Kerry]

Kerry: Not ME groups, I’ve got friends that I email.

Mark: Right, I can give you my email address, I mean I haven’t got the website, but I’m now excluding - or partially excluded, ’cause it’s only for people in their twenties. [All laugh.] So I’ve kind of been booted out really. [More laughter.] But there is a really good group of people on there.

Kerry: Oh good that would be great!

Mark: So and there’s somebody from round your way. Erm, I can’t remember where it is but there’s a girl that lives very close to where you are.

Kerry: Yeah that would be really good
Focus Group 3: 15th March 2005 at 2.00pm.
Three Participants that had been Discharged from CFS Service

Mark: Have you got a piece of paper?

I: Yeah sure. So is everyone feeling okay? [All participants say yes.]

Mark: Is there any other websites or advice things you know of for ME?

I: This has come up in other groups, and to be honest with you I don’t know, but if I do find out I will post the information to all participants.

Mark: Right thanks!

Group ends. All participants thank each other and say goodbye - then leave the room.
Transcription Four
Interview Conducted on Friday 1st April 2005 with one participant.

Comments: One out of five participants attended the focus group discussion - no message was received from the participants who did not attend (although there were no administration staff at the University Department of Clinical Psychologist when I contacted them at 1.15pm on 01/04/05). The participant did not mind waiting until 1.30pm for the interview to commence (to allow time for possible late attendees). The two group facilitators had discussed how they should proceed with one participant, in terms of trying to rearrange or whether the second facilitator should not be present in the one-to-one interview. The participant stated that she felt comfortable to talk in the presence of another interviewer, and so an individual interview proceeded as follows.

The lead facilitator orientated the participant to the focus of the discussion, which was looking at peoples’ relationship experiences with CFS and the Health Service. The participant was informed about confidentiality, and how the results will be dealt with. She was given the option to ask questions, which she declined.

1 I: I'm aware that you are currently receiving treatment from
2 the [name of city] CFS Service. I was wondering how you
3 have found this so far?
4
5 Helen: Well fortunately I've been accepted at the Chronic
6 Fatigue Unit, and err, I got accepted a year earlier because I
7 work for the same Trust. So my Occupational Health Doctor
8 did actually write and, err (1). So I got accepted and saw,
9 had my first appointment in December, and expected
10 treatment to start in January, but due to sickness and annual
11 leave been at the end of, like the financial year, erm, I've
12 only had one appointment of treatment, and I haven't got
13 another appointment booked yet. (I: Okay.) So [laughs] I
14 don't really know what's happening! They've not contacted
15 me, so I suppose I'll need to contact them.
Interview Conducted on Friday 1st April 2005 with one participant.

I: Right, so has your experience so far met with your expectations?

Helen: Well when I started at the end of January, I thought by sort of like, well now we are at the beginning of April, I'd thought yeah, I'd be well into it. And we'd be thinking about returning to work in the summer. But I've had one appointment, and that was just on what Chronic Fatigue is.

(I: Right okay.) So, I'd been on the Internet and everything, I was well read on it.

I: So you felt that you already knew a lot about Chronic Fatigue. So you attended an assessment?

Helen: Yes with the Senior O.T. [name of therapist].

I: And will you be seeing [name of therapist]? (Helen: Yes.)

I: What are your expectations of therapy?

Helen: Erm, well I've filled in my charts for two weeks about what my activities are - which the next time I see [name of therapist], she'll go through with me, to sort of establish a baseline. And then hopefully, it's advice sort of on
like erm, maintaining the energy I have got, and how to actually progress, 'cause I seem to have plateaued out a bit [laughs]. I'd been doing all right, and I seem to have plateaued out. So hopefully, with [name of therapist]'s advice, that we're gonna be able to step it up, and I'm going to keep getting her to step my energy up. (I: Right.) Erm, and looking at going back to work. And erm, there's the cognitive behavioural therapy as well - whether she does it or somebody else, I'm not really sure - about looking where I'm at and erm, and then hopefully in building me to go back to work, 'cause it's the same Trust, hopefully, it's going to be looking at, you know, it's going to overlap with me going back to work. Well that's what I'm hoping anyhow! [laughs]. So I've still got [name of therapist] while I'm still trying to go back to work. And I'll be going back to work on therapeutic hours. Which is part of the Trust policy to go back to work on therapeutic hours.

I: What are therapeutic hours?

Helen: Well therapeutic hours are, I can work up to - I still stay on the sick, and still be covered with a sick note, and I'm still - well I don't get paid now as I've been off for over a year. But I'll go back to work, and I can work up to sixteen hours a week. (I: Right.) And I'm supernumerary, and it's
just to get back orientated into the job and the office and the
people and what’s going on. And, if during the day I feel
tired or feel ill I can just go home ‘cause I’m supernumerary.
And it depends on my Occupational Health Doctor how long
I do that for, on average it’s about a month, but I think he’s
thinking about two months for me. Em, and then, when I’m
happy, then, well everybody’s happy, then I go back to work,
and resume my job. (I: Right.) And then all the time that
I’ve had at work I’ll have back as time owing.

I: Right, well that sounds like a good policy.

Helen: Yeah I thought that was quite good as well. But
work are quite limited - they want to limit me, ‘cause
obviously the amount of time owing I’m going to have, they
are going to have to give me back. So they are a bit [pulls an
expression showing stress] about me doing it for two months.
So I will just have to see.

I: So do you feel your work colleagues have been
supportive?

Helen: [clears throat] Erm (1) yes and no. Yes in that they
followed the sick procedure, as in, erm (1) I’ve had regular
sick reviews, the first six months, which is with my initial
Line Manager, the G Grade - erm, and now it's with, erm, the
Team Leader, my Union Rep and Personnel. And they're
regular and they just say, "Yes, how are you doing?" But
from the point of why I was sick in the first place, which was
caused by, or in my belief, stress at work - I don't feel that's
been addressed, and I'm still quite bothered about that! (I:
Yes.) That, you know, work has contributed, in my belief, to
my illness. And nobody's actually sat down and said, "Well
alright then - we can't change what's happened. But, you
know, we will support you or take on board what's happened
or (1)." 'Cause I could say about going back to work but just
be in exactly the same boat [laughs]. So, I think that that's
my only thing from work that I, I've tried to address, but it's
been half-heartedly, "Yes okay, we're dealing with it." But
nothing's concretely been said, you know, like this is
happening or we will look at this when you get back to work.
So that's one of the things I'm going to try and get in-built
when I do go back. But, and also because of the nature of the
illness, you know I don't want to be negative and sort of like
say, if I go and relapse or whatever - but obviously it's in the
back of my mind. I want to stay positive, you know but it's
in the back of my mind that if I go back into a totally stressful
situation that I'd left, that I'm gonna sort of like end back in
this spiral, or whatever again.
I: That sounds like a difficult situation to manage. So there
is a part of you that wants to go back to work but you are
aware of the risks that are attached to that.

Helen: Yeah and it's how much work is going to take on
board. I had a sick review last week and I did say, “You
know, I'm concerned about the staff’s attitudes to me when I
do go back.” ‘Cause obviously, this sort of illness there's a
lot of controversy around it anyhow [laughs] and it depends
who you talk to, whether you're a medic or psychiatrist, what
you believe or, do you know what I mean? And people at
work - they have seen me, I mean I have been in touch and
been in work (XXX), and tried to keep in touch with them,
and they're just like, “Oh you're looking well.” But inside
they can't see, you know, all the pains and the aches, the pins
and needles, all the other bits and pieces that are going on in
me. And, I think they kind of think - they don't understand
where I'm coming from, they don't understand why I'm still
off, and (1), you know, they don't - so one of the things I
have asked when I go back to work is that there is some sort
of awareness about my, my illness. ‘Cause am I going back
cured, am I going back just in relapse, you know? And I
don't want them to think, “Oh yeah, C’s back, you know,
she's back in her job here you are,” boom, “here's your
caseload.” You know, off you go, and six months later I'm,
you know, I'm ill again. So (2) - but work has said that we
can do some sort of awareness, but it's, it's me as well, can -
have I got the guts to turn round and say, "Well no I can't do
it 'cause I'm not well today." Do you know what I mean? I
don't want to let people down, and (2). I don't know.
perhaps I'm being, sort of overly-bothered about it. It will
probably not be that bad, I'm probably thinking of the worst
scenario when I go back. But, it's still - I feel that I need to
protect myself because (1) despite the stress last year, and me
speaking up at work that I was stressed, nobody did anything
to help me. So I feel I have to put this like, protection around
me when I go back. (I: Yeah.) Because I've got to protect
my health, and you know, not put my family through what
they've gone through as well.

I: When you said that you were stressed at work, were your
colleagues stressed as well?

Helen: There was a lot of stress, it was, it was a very unusual
situation in that my line manager, my G Grade, was on the
sick, and the Team Leader was on the sick [laughs]. So I had
another G Grade that was sort of overseeing, and he was
really really stressed. He was just a general pig to all of us,
but I got the brunt of it because I'm the F Grade. Erm, and,
there was an unusual circumstance with a particular case that
(1) I wouldn’t normally be in, so, erm, it was very stressful. So it was an unusual situation, and I know I’m not going to be going back to that exact situation, but it does bother me that (2), you know, things can happen. But, you know, I did say, “I’m stressed” when I had supervision, and everything was written down, but nothing practical was ever done. (I: Right.) And that’s what I wanted to happen. I don’t know what, perhaps I’m just imagining that (1), that they should be doing things that was impossible. I don’t know, but I just didn’t feel that I was looked, you know, looked after. I became very cynical about my job, and (1), ‘cause my job’s been my career - well now it’s - it’s just a job. When I go back it’s just a job. My whole view of my job’s changed. Because I feel very cynical about what’s happened to me by the Trust I work for.

I: Right, so is that a negative thing then, that you see your work as just a job?

Helen: No I think, erm, in the last twelve months I’ve totally re-evaluated my life, and my priorities have changed. I’ve been very much, ambitious, well, driven and want to get on [laughs]. And suddenly, with being ill, it’s like well hang on a minute, is this happening, you know, I believe this is all happening for a reason and I’m just trying to work out what
the reason is. My priorities have changed, in that I've become totally more family-orientated, and (1) - my family was never neglected, you know, we always did things. It's, it's just this, I've just changed, I've just sort of like changed the, you know, that my family are more important, and I will go back to nursing, but in a few years time I want out of nursing now. I'm so “Grrrrr,” about what's happened [laughs].

I: So what do you foresee in your future?

Helen: Ermmm, (2) short-term and not quite sure which way I'm going to go - long-term, erm, I want to sort of work more, sort of abroad. I've want, wanted to work abroad. I think I'd move abroad if it wasn't for my daughter because I'm not with her dad - so (2) both my husband and I would like to go and do some - like work in Africa or sort of voluntary work or something abroad. But that's sort of like long-term. How I get from where I am now to that, where I do some voluntary work, erm - cause when I go back to work I'm only going back part-time. So, you know, that's where I sort of - it's still going to be something to do with the caring profession, but not for an NHS Trust. [Laughs.]
I: Right, because you feel let down by them? (Helen: Mmm yes exactly.) So you’ve spoken about possibly moving abroad to do some voluntary work with your husband, have you developed the plan since the CFS started?

Helen: No that’s been something, well it’s been in the back of my mind for years- but I’ve never had the guts to do it. [laughs]. I’d like to be able to do it but ooh arranging it and doing it, it’s a different matter, but erm, long-term, I mean my daughter’s only nine - so you know, we’re not looking at within the next five years- probably, sort of, the next ten years or something.

I: Do you think that when you were working before you had CFS you had developed your future plans?

Helen: No, not at all, not at all. It was, it was just like living, I suppose, from day-to-day, and thinking, “Yeah one day I will do it, and one day I will think about it.” I mean, not just that, just sort of anything, any hobbies or interests or whatever. You know, it’s like, when I’ve got time I’ll do that, or decorate the house even or anything. Do you know what I mean, it’s like “I will get round to that, I will get round to it”, but never did, because it was just every day sort of like every day, just living. You know, in the fast lane, you
know, just surviving, make sure the bills are paid, you go to
work and my daughter's at school - you know, just all the
basic stuff, it's just hard work.

I: So there's kind of two sides to the situation, in that the
CFS along side making you ill - it seems to have given you
time to re-evaluate your life and decide what is important
(Helen: Mmm.) And the Trust that you feel let down by -
has also **personally** done you some favours as well?

Helen: **Absolutely**, absolutely. You know I've always, you
know I have my down days, you know, I could just sit and
cry some days and think, "What the Hell's happening?" But
I suppose because I'm quite an open and spiritual person, I, I
try and see the bigger picture, and I suppose that's really been
since the beginning of December that I've sort of like, got to
grips with being ill and this is where I'm at, and I've sort of
seen the bigger picture. I want what's happened in the last
twelve months to, **to mean something**, do you know what I
mean, I don't want it to just be - go back to how it was, and
I've not learnt anything from it or not made any changes
because of it. 'Cause I do believe - 'cause when I look over
my life, I mean, my stress, I do get stressed, and different
things that have happened in my life, and I feel like it has all
built up to like, this moment. In that, I've perhaps had signs
of things happening before, and you just like shrug it away and you just sort of like carry on. And I think in the end my body’s just turned round and said, “Hang up a minute! You know, you can’t keep going on like you have been.” And another thing is, is that I’m a very impatient person. Well with CFS you can’t, just like forget about it, or “Today I’m going to be well”, cause you can’t do with it. And I’ve had to really learn to like sit with it, which has been one of the hardest things I’ve had to do. Because I just wanna like, well if I want to do something I’ll go and do it! You know, like before, whereas now have to think, “Well I can’t, or or, you know, I physically can’t do something, and erm, I can’t sort of pretend I’ve not got it today”. You know it’s always there! And, it’s, I think that’s been one of the biggest things is patience I think, I’ve got to just sit and wait or whatever gonna happen with my treatment or, you know, that’s been a big thing for me.

I: Would you say that you’re a more patient person now?

[Helen shakes head and laughs]: No. [Both laugh.] Okay so you’ve learnt to cope with inpatient.

Helen: Well yeah, I think I’m learning, but I think I’ve, I need to sort of like, erm, transfer the patience bit that I’m learning from CFS to other areas of my life. I can still be
inpatient about, you know, I don’t know, waiting - I’m ready to go out and waiting for my husband or whatever, and I can be like [sucks in air through teeth], you know. But, you know I have to transfer that skill that I’ve got to sit with the illness to everyday things. And that’s I suppose the point that I’m at, at the moment, where I just sort of like need to chill a bit. [Laughs.]

I: Yes and that’s hard to do when you have struggled with patience. Other participants in the groups I have facilitated have talked about, as you have, being high achievers, being motivated and career-orientated. Then CFS comes along and knocks you off track. It’s interesting, and you have obviously reflected a lot about your life, and tried to make sense about what has happened to you and why - and you said that stress you were under at work was a major contributory factor to becoming unwell. I just wondered if you can think of other factors that may have contributed to the onset of CFS?

Helen: Well (2) there’s one other major thing, I mean, my marriage and everything, my relationship with my daughter and everything is fantastic. I’ve been married for five years, and he is fourteen years younger than me. The only issue that was going on in our marriage at the time was that - I’ve just
turned forty (2) and, err, in January, and James was twenty-six. And I’ve got a daughter from a previous relationship, and we were talking about starting a family. And that was a big issue, erm, I suppose about the time I become ill but we’d been trying sort of, for about five or six months. And, erm, because I was really stressed, that, I felt that it was stress that was contributing to the fact as well that I wasn’t getting pregnant. So course each month it was very disappointing— and as much as I was trying not to be disappointed every month [laughs], it was just like; well I’d think, “Ooh the biological clock’s ticking.” And it’s a big decision about us having a baby, cause we were not bothered either way, but (2) it was just one of those things, “Am I going to regret it when I’m a few years older - James has not got a child.” So that was going on at the same time. And, erm (2), and I see, sort of like the ME, sort of a bit of like, “Ooh it’s stopped my plans, ‘cause I’m like forty now and I’m not pregnant, and it’s like ERRRRH.” You know, so I see that as a bit of a hiccup for James and I as well, and, I mean we have been tested, there’s no reason why we can’t. But, erm, and I’ve also got, erm, erm, low hypothyroidism, which got diagnosed whilst I’ve been off. So it’s like all that, like “Oh, we’re not going to have a baby then.” And I, I’m not devastated but (2), it’s just one of those issues that we felt, if I was twenty-six we’d have a lot of years to sort of like plan and think
about when it was ready - but because my biological clock
was ticking away, I felt like [gasp] I’ve got to make a
decision, and what happens if I make the wrong decision? So,
sort of like (2), sort of like six months before I, well I became
ill in the March, so about five or six months before that we
had made a decision sort of like, yeah we’ll try, and if it’s
meant to be it’s meant to be! But erm, I think you know,
with having like the ME, it’s like, “Ooh is this stopping me.”
It’s made me resent it a bit as well. But, if it’s not meant to be
then it’s not going to happen, and I just have to try and be
philosophical about it, and not think too much about it. Even
though I’ve got these like three baby nieces and nephews
around, four baby nieces and nephews around at the moment,
it’s like [takes an exaggerated intake of air then laughs]. But
that’s the only thing that was actually going on at the time -
was work and then this major decision, and deciding what we
was going to do. But there was nothing, nothing else major
going on that I’d got any worries about.

I: Right. So there were two pressured things going on at the
time (Helen: Yes.) Even though you say, “What will be will
be”, well I guess if you’re trying you’re trying. (Helen:
That’s right yes.) You said something earlier about your
spirituality, and seeing the bigger picture, what does the
picture look like?
Helen: Erm, (2), I think it’s just been, I mean spirituality has only been sort of like something that I’ve addressed, I suppose in the last four years and that’s been ‘cause I was influenced by somebody that has came to work in the office. And, erm, four of us in the office, we all became spiritual and got into our angels, and I’ve been reading up, and sort of like become, sort of like quite a spiritual person. I just read it, it’s something that’s private to me, and I don’t go to spiritualist church or anything like that. It was just really to see, sort of erm, about what life is about - what the meaning of life is. And I suppose one of the things is like, what is my role in life? And am I fulfilling it? Am I fulfilling my destiny as it were, and err, and I’ve done a lot of reading and I’ve got these archetype like cards that I’ve got as well. I’m trying to work out my personality; I mean I’m into all that [laughs]. Erm, and, I just seem to be drawn to that, it just seemed important for me to find out what life was about for me. And I did have a big thing about, oh years ago, about four or five years ago, about dying - which I’ve got no fear about that now at all because I believe in like reincarnation and everything. So, it has been a major major thing to me, but it is a lot of comfort - but it’s not like you’re church bible bashing, sort of dogmatic things from the church, it’s just spiritual that gives me a lot of comfort.
I: Sure, and what did you find out about your role?

Helen: I'm erm, I'm a rescuer- which is something that - I suppose that's why I'm in nursing. But, I think it's more, it's, all of it still came down to me, sort of like, the healing role, the sort of like caring role. You know, all that - well I say "nursy nursing"- but not necessarily in a nursing way. I mean, more sort of like the voluntary work I suppose now. And erm, but it was, it was all around sort of like working with people. (I: Yeah.) But it's just that I want to save the world! That's because I am too much of a rescuer [laughs]. You know, I want to be able to, you know, like with my job, I want to be able to go in and solve - cause I go into families - I want to solve all their problems and obviously I can't do that.

I: What's it like when you can't solve people's problems?

Helen: I just beat myself up over it. I just say to myself that, you know, "Oh well I've failed as a Community Nurse, or as a human being, or", (1), "whatever." You know, but I can't, that's one of the things that I've realised. I had a big conversation, ooh I few weeks ago now, with my dad of all people. And he was, because my dad was all very ambitious, that's where I get it all from. And even my dad says, "Ooh,
when you've got your twenty years pension, you can leave
and go and work in Tesco or somewhere,” [laughing], which
for my dad to say, is, and had this big conversation (2) about
drive and about ambition. And he was saying, “You want to
go in and solve everybody’s problems and you just can’t.”
And he was saying, you know, “Just go in and do what you
can, maintain them but, you know, stop beating yourself up if
you can’t wave your magic wand, ‘cause you haven’t got
one”.

I: What was that like, to hear your dad say that?

Helen: It was really weird. Because it was just like, you
know, my dad has always wanted us to do well, and out of
my brother and I - we’ve both done well, but I’m the one that
had the career and sort of like, gone up the ladder, and you
know studied and whatever. And it, it felt like a lot of
pressure was taken off me, ‘cause I think a lot of things that
I’ve done has been ‘cause I want my dad to be pleased. And
he’s like given me permission to jack it all in if I want. And
that was like, “Great, thanks dad,” [laughs].

I: So you found the conversation quite liberating?
Helen: Yes it is. Particularly to have that sort of conversation with my dad as well - cause he's very authoritarian stiff upper lip sort. But to have that with him, and erm, and for him to say, "Look you know, do what you have to do. Don't worry about your mum or I, or whatever." Like you say, it was quite liberating, 'cause it was like oh well I can - I'm forty and I'm getting my dad's permission [laughs].

I: Well parental relationships are important.

Helen: Yes, I'm very close to my mum and dad.

I: How would you describe your mother?

Helen: My mum's erm, (2), my mum's a martyr. Family come first, everything comes before, you know, her needs come last on the list. And I think a few things she's said in conversation over recent years, is that I think she looks back on life and regrets things that she's not done. And she's not been confident to it. So she's always pushed me to do things I think, so it's like, "Well if you want to go and do it, if you want to go and work abroad, go and do it! But she wouldn't go and do anything for herself, you know, but I think she does regret putting us all first and not allowing herself, you
know, I think she’s always been brought up to think it’s selfish to think of yourself first.

I: Do you think that too?

Helen: Yeah, I have done, yeah. I think in recent years I’ve tried to address it. The reason why I’ve addressed a lot of things is because erm, I suppose it’s four or five years ago I started a three-year training to do erm, person-centred counselling. So I’m a qualified counsellor. So, I suppose I’ve looked at myself quite a lot then, and that’s where a lot of my self-awareness came from, so, that’s how come I know myself.

I: And the CFS sounds like something that has - well it has stopped some of your plans - but it sounds like it has also made you think more about yourself. (Helen: Yes.) I know that there are cognitive symptoms of CFS, but in a sense when your body is not able to do things you have got time to reflect on your life. (Helen: Yes.) I was interested in what you were saying about your parents, in that your dad wanted you to achieve success and your mum wanted to almost live through you - that sounds like a lot of pressure.
Helen: Yes very much so. Dad always wanted the best for us. I wanted to be a nanny when I was sixteen, now I was going to live abroad and be a nanny, see I’ve always wanted to work abroad! It wasn’t good enough for my dad, and he wanted me to be a school teacher, “You can do better!” He persuaded me to stay on at sixth form, and I, I think that is the first real memory I’ve got of, my dad, you know, sort of like, you know looking back, cause obviously I look back a lot thinking about how much my dad influenced me. And that was, at the time it didn’t seem much, but when I look back now, that is a big sort of thing in my life. That I never went down the path that I originally wanted to go on, because my dad knew something I’d had a bad experience, he didn’t want me to go abroad because he couldn’t keep me safe [laughs]. So, you know, and at the time I was just like, “Yeah, well all right, whatever.” And I went into sixth form, dropped two ‘A’ Levels, I couldn’t cope with sixth form - I hated it! You know, it was just a time for messing around in the Common Room, and [laughs] discovering boys [laughs] and all that sort of stuff. I didn’t want all of that (1) pressure. I didn’t want to go to university or anything. But erm, you know, and I managed, you know, and I eventually got into nursing, but err, you know, at the time I just thought, “Okay fine,” accepted it but now I can be quite, (1) quite bitter about it if I let myself. You know, dad didn’t let me do what I
wanted to do! But, you know, it’s all water under the bridge now. But, there was a lot of pressure. I don’t know how much, my dad did put pressure on us, but I think I also increased that pressure. (I: Right.) It was like, you know, how much did my dad really want me to do, or how much did I think my dad wanted me to do? So I think I put that extra pressure on myself as well, I can’t blame it all on my dad [laughs].

I: Right, and you said like you have some similar qualities. (Helen: Yes.) I wanted to go back to something that you said earlier. I wondered what makes somebody a rescuer? What makes somebody want to “fix” other people?

Helen: Erm (2), some of me, I think, was, I don’t know what to call it! I suppose the reward, the pay-off for actually helping somebody, or self-worth that I could help somebody, and you know, you saw their life improve and they thank you or whatever. I think it was some of that, you know, my personal self-worth for my own self-esteem as well that I’d helped somebody. That made me feel good as well, as well as them feeling good, it’s not always just about the self is it. That it was very much I think, you know, I got a pat on the back for it, or whatever, and I needed that! I needed - I suppose ‘cause my self-esteem was probably low I needed
almost to feed on me helping somebody else to build up my
own self-esteem.

I: Yes. So what would you say your self-esteem is like now?

Helen: Erm, depends on what sort of day I’m having, if I’m
having a positive day, I can be quite, yeah, I’m on track, I’m
okay, I will be okay. But then on a bad day, I’m just like,
“Oh I’m so crap,” [laughs]. I think I’ve got quite low self-
esteeem, like I say, it depends on the day how I view it,
negative or positive. You know, like on a good day I can
have low self-esteem but I can think, “Yeah I know I’ll get
better.” But on a bad day I’ll think, “Well I’ll always be like
this, I’m always going to be crap.” It depends on which way
the wind’s blowing [laugh together]. But I’d say on the
whole I’ve got quite low self-esteem.

I: Do you attribute that to striving to please others or
something else?

Helen: I think that’s how - I’ve just always been like that.
Always, I was never in trouble at school - I just always
wanted to please, and you know, be good and get praised, and
you know, get recognised for it - the same at home. I wasn’t
always a little saint at home - I did have a bit of a gob on me
[both laugh]. Because I would try and stand up for my rights.

Or what I believed or my opinions, but because my dad was really strong it was just totally shot down in flames, I was - so I backed down and I still do that now. Confrontation I back down straight away, 'cause everybody else is right and I'm wrong - because that was like the relationship I had with my dad.

I: Yes, and you are aware of repeating patterns. When you were talking about your father, I don’t know if this sounds a bit odd - but I pictured you as a little girl getting squashed in a way.

Helen: Yes very much so, very much so yes.

I: Yes it certainly comes across that you are reflective, and you sound like you have pieced things together from your past, because I guess you are who you are and also the kind of job that you do. How do you think you coped with that pressure to please as a child? I guess what I mean is how has this affected your current relationships?

Helen: I think I want more from people. I think I’ve lived a lot of my life through what I think other people want me to do, particularly my parents. Erm (2), I wouldn’t say - in
some ways I’m independent, erm, but in a lot of ways I
would say I rely on other people for that, for that feedback.
I’m not sort of a person who can be on my own. It’s like in
relationships with men, if a relationship’s been failing, I
wouldn’t split with that relationship until someone else was
there to replace it. It was like, I couldn’t be on my own, and I
couldn’t survive on my own. But, I suppose yeah, I am
influenced a lot by people around me.

I: Right, and let’s think of it in terms of CFS. If you imagine
CFS to be person, how would you describe your relationship
with that person?

Helen: Erm, (4) it’s really hard to sort of like say.

I: Yes it is. Well what would CFS look like if you had to
describe it, what would it look like?

Helen: Erm, (6), I don’t know really, erm, (3), I don’t know,
somebody quite strong, quite dominant. (I: Yes.) Yeah sort
of powerful, strong.

I: Okay, powerful and strong (2) and in what why does that
affect you?
Helen: Well it’s controlling my life at the moment. I can’t get away from it - I can’t (3). You know, ‘cause even if I try and stand up to it, it’s almost like, it’s like the confrontation thing, you know. If I was trying to stand up for myself, like you say, I could be squashed, and I suppose that’s what I see. Because I’ve tried lots of things, I’ve read up on things, I’ve had alternative therapies, you know, I’ve really tried to research it and help myself. And, (2) and then at the end of the day I just seem to get squashed by the illness again. I sort of like seem to take a step forward and then about three back! That’s how it feels, you know, and I get quite sort of frustrated with that. (I: Yes.) But then there’s still something in me that hasn’t gone, “All right, I give up to it, I’m just gonna lie down,” [laughs]. And just sort of like, go in a corner somewhere. But I still sort of like come out fighting. ‘Cause I suppose that’s that drive thing that I’ve got to overcome it - you know, I’ve got to make this count or, you know, make the changes or whatever. And I just think that it’s a process of how I feel now about it is obviously different to how I felt six months ago. So it’s been a process of how things have happened and how my view has changed towards my illness. You know, you have to go through processes don’t you.
I: Yeah, sure. Do you think that process is what everybody would go through who had ME? Or do you think there are things about you as a person - your personality if you like, that would influence the process that you would go through?

Helen: Yeah I think so. I think it does depend on the individual. You know, this is just my opinion. (I: Yeah, sure.) Cause I've read about people that have had it for years and years, and I couldn't imagine being ill that long. And erm, and I just think that because I have this personality- that I see a problem and I have to solve it, that, and I have got that awareness and that drive, I don't know - it might even hinder me, you know. This could be because I've hindered myself, because I've been so wrapped up - particularly the first six months about - “Why am I ill? Why me?” And all that!

[Laughs.] You know I've got to find out! That in the end I've just had to let that go. I suppose like, what I was saying, it's part of the process. But (2) erm, I do think that because I got this sort of awareness and 'cause of my spirituality and seeing the bigger picture, that I could imagine that people who haven't got that, and, sort of the support I've had at home with my husband, that, you know, you could just say, “No, you're better just staying in all week.” I could just see people, you know, de-conditioning and sort of not having no social contact and becoming more down and depressed. I can
see, that, you know, people getting like that and the illness
prolonging.

I: So in a sense then, what you are saying is that if you don't
fight it - it will beat you - you will succumb to it and become
depressed?

Helen: Erm (3). I don't necessarily think that fighting it has
been right for me as well. 'Cause sometimes, 'cause I have
been fighting it - then I have a bad day - I just think I'm
failing. So [laughs], so then I beat myself up about it. I think
I probably go to the extreme [laughs]. You know, by really
fighting it, and I've got to like - you know, I think I've had to
lay off it a little bit and sort of be a bit more realistic about
(2) seeing it as the enemy I suppose. More like accepting it,
this is where I'm at and, I've got it and for whatever reason -
I mean it's been important that I find out why, because I
don't want it to happen again. And I feel if you find out why
something has happened then you won't let it happen again.
But I can't, you can't always - I've got an idea of what's
contributed to it, but, and I suppose that I just have to be
happy with that - an educated guess I suppose.

I: This is the thing with CFS though isn't it, there is no
agreed cause, and there is no agreed treatment. The
Transcription Four
Interview Conducted on Friday 1st April 2005 with one participant.

688 evidence-base points to CBT and Pacing, but as you know
689 that these things don't work for everyone. As you know
690 when you have delivered interventions yourself. In terms of
691 the Service, the CFS Service, if I could give you a magic
692 wand, what would it be like?
693
694 Helen: Erm (2). I mean the thing is as well, like I said
695 before about the controversy of the illness, because there is
696 no definite diagnosis, and it depends on who you talk to
697 whether it is medical, or whether it is emotional or
698 psychological. And, I think from like, going to the [name of
699 the Mental Health Ward where the CFS is based], it's sort of
700 like, "Oh is it a psychological mental illness and," (2) you
701 know, so it's like, I feel it's more like that approach and it's
702 not necessarily addressing perhaps physical things that are
703 going on with me. So, because it seems very split, the illness
704 about - like I say, whether you're in medical or whether it's
705 you know, psychiatry. I just feel that it needs to merge a bit
706 more, do you know what I mean? And it's err, (2) and (1) I
707 just feel that the approach is that, that I'm getting from the
708 Unit is more - with it being cognitive-behavioural, it's just
709 more emotional. And I know it's part of it! You know, from
710 experiencing it myself I believe it's a bit of both. You know,
711 I can't say it's psychological, I can't just say it's just medical;
712 I believe it's a combination. I just feel that (1) I don't know -
whether it's more about me just having a hang-up about
having a mental illness or a psychological problem I don't
know. But I just feel it seems more orientated towards that if
you see what I mean.

I: Yes I do understand and I think that is an issue for lots of
people. In terms of that, would it better if it was in a more
neutral building? Or is it because the service comes under
the umbrella of psychiatry in [name of city].

Helen: Yeah I think it is, and also, I suppose, I mean I've not
spoke to my people at work, but obviously we work for the
same - we work in the [name of speciality], and that is still
part of our service but in mental health. They're not
understanding my illness and they see that I'm going to the
[name of Mental Health Ward]. [Sucks in breath through
teeth then laughs.] It's like, "Ooh what are they thinking!?"
Or is this just me in my head or or whatever. I just feel that it
ought to be a neutral sort of thing and sort of like, yeah like I
say, there probably is a bit of both, but it just seems that it is
mainly aimed at sort of more psychological then (3).

I: Yes it seems that there is a psychological versus physical
health debate regarding CFS that has somewhat plagued
peoples’ experiences and preoccupied researchers and
professionals for a long time.

Helen: Yeah I think ‘cause just in the press and everything -
it’s, it’s just controversial and everything as well. You know,
obviously it’s improved from like the eighties when it was
called “Yuppie Flu” and whatever. Because it is an illness
that can’t be proved under a microscope or whatever, then it’s
got to be in your head or you’re just imagining it. And (2)
you know obviously things have changed since like the
eighties, but there are still a lot of negative people out there
that don’t understand it or see it as it is just all in your head -
and you’ve brought it on yourself. And - and it’s probably
things that I’ve asked myself as well [laughs]. You know
like have I brought this on myself because I erm (2) you
know, I’m psychologically not balancing or whatever you
know. So it’s just something that has gone through my head
for myself as well.

I: I guess it’s very difficult to understand an illness when
there is no mainstream agreement about the illness. And as
you said, it may depend on whom you talk to as to what
opinion they will have about it. So in that sense it is bound to
impact on you isn’t it?
Helen: And also cause like I have a real thing about what people think of me. And, I like to blend in, I don’t like to be centre of attention [laughs]. I like to just blend in and just be like part of like the team or whatever. But because I’ve got this illness and there is this controversy around it, and also working with people that don’t understand it, and I’m going to the [name of Mental Health Ward], then it’s bothering me what I think they’re thinking of me. Which is, you know, am I being, I know all about labelling and being stigmatised, I work with [name of client group she works with]. So (2) and I know how they get labelled, and I’m thinking, “Well are people (1)”, - people probably aren’t even thinking about it! But you know what it’s like! You just think, “Well are people (1) or.” And I suppose that - that bothers me ‘cause obviously when I go back to work I need to explain to them what’s going on and they need to sort of understand my illness. And, you know, if I’ve got this mental illness stigma attached to it ‘cause they see me go to the [name of mental health ward] it’s (2) you know. It bothers me but that says more about me than them. (3) You know.

I: What do you think would help you cope with your concerns about what people think of you?
Helen: Erm (3). Well from work, I mean I’m - we are going
to go in or whether we get [name of therapist] to go in and
talk to the staff; ‘cause it’s the same Trust. Or whether I go
in and do some sort of awareness, erm, a lot of it will be done
through my Occupational Health Doctor as well, ‘cause he’s
obviously going to be putting into place what I’m going to
do when I go back to work and the guidelines. So hopefully
that’s going to help. But the main thing is about; erm, what I
say me, how I view it - or how I think other people are
viewing me. And that’s something I need to address for
myself. So that in the future if anything comes up it doesn’t
really matter what anybody else thinks. I’d like to be like
that, and don’t care if they think I’ve got mental health
problems, I know what it is, do you know what I mean? But
I also feel that I have to justify myself - and, you know,
where I’m at; what I’m doing; why am I like I am, and you
know, and that’s something I would like to change about
myself. To be more like “I don’t care what you think!”

I: That sounds like you want to change something that is
very intrinsic to you, as you said yourself, you have tried to
please others since you were a little girl.

Helen: I’ve been like aware for quite a lot of years about
things that make up my personality, like this drive and
everything- I’ve been aware of it, I’ve been aware of it. And
things happen and like I get angry about something, and I just
put it down to my personality, I go “Well that’s me!” But I
suppose recently I’ve been thinking, “Okay that’s all right
that it’s me, but I could also challenge that.” And I’ve
always just accepted that that is my personality - but I really
believe now that I can challenge things in personality and
make some changes. (I: Right okay.) Which, you know, in
rather than just accepting that’s me because I’m a mardy cow
or I get really angry or whatever [laughs]. But, you know, I
can say well, you know, have I got any grounds to it? And
actually challenge it, and perhaps try and rationalise it a bit
more than it being irrational. And that’s what I’d like to do
about a lot of things. And that’s when I think about having
the ME, is that I’ve been aware of all these things but I’ve not
done anything about it - and now is the time that I have to
address them. How - I’m not quite sure but (2) it will
happen, [laughs] bits of it will happen. You know, when I
say I want this to count, that’s part of it as well, it’s changing
the parts of my personality that I can change or challenge or
(2). You know, just because I feel it or it’s a habit or
whatever it doesn’t necessarily mean that it is right for me so
(2) that’s what I’m hoping to do [laughs].
I: Right. So if we go back to your experiences of the CFS Service, you have had one appointment to date, which was in January?

Helen: I mean [name of therapist]’s really nice, I hit it off with her straight away. I felt very comfortable with her. And (2) and I felt straight away, you know, that I could talk to her and just really be open with her. I did feel a bit - when she gave me some information on Trudy Chandler? Or somebody or other - some information book that she’d photocopied for me about the approach that they use, and about like filling in your timetable for like two weeks - and then it’s going to be like put under the microscope - and I feel a bit [gasps] defensive over that! But I’m sure that – ‘cause [name of therapist] is so nice, you know, I think she’ll (2) she’ll gently [laughs] she’ll gently say, “Well perhaps.” ‘Cause I’ve said to her, you know, if you criticise me I’m going to be [sucks in air suddenly] - so she knows! I think she’ll be fine.

I: Okay so you sound like you have an optimistic view of your future therapeutic relationship. And the important thing is that she is listening and she is nice and you can be honest with her.
Helen: Yes definitely. She seemed to know where I was going from when I was saying things - you know, obviously from her experience with other people, ‘cause I haven’t really met anyone who has got ME or really talked to them so (1). Yeah because like GPs, and you know doctors have been a bit vague about things - to actually talk to somebody that was finally like, “Yeah, I know where you are coming from!” That was a great relief. You know like, “I’m not going mad. There are other people out there like me!” Do you know what I mean? (I: Sure.) Within - being - having ME I’m normal do you know what I mean?

I: Yes I do. I feel in some ways we have managed to get much more in-depth about personal reflections because it is just you and I talking. But in other ways it’s a shame that other people didn’t come to the discussion, because for many of them it was the first time they had met other people with CFS. I’ve been struck by the impact that has had on people. It has seemed very important to share experiences with each other and feel accepted. I feel sad that you have not had that opportunity. Again, in terms of the CFS service, if I was to say to you what would an awful therapeutic relationship consist of, what comes to mind?
Helen: I suppose it would depend on their personality, you know, their experience - obviously [name of therapist] had got experience of it and understood - she’d heard it, you know, all before, you know. I suppose obviously people have to start at the beginning, so if it had been somebody new that obviously didn’t understand, and I think it’s the people skills as well! You know, in how we sat, I think from just meeting her straight away, you know, it, it, there was just something there that - and I don’t know if it was because she was a woman. I mean I don’t know how I would have been if it was a bloke. Erm, I met the erm [name of Consultant], and he just scared me to death! It was just like [inhales sharply and loudly to indicate horror]. I, I met him as erm, (1) in his private capacity, because I’m making a claim with [name of Insurance Company] for my income protection, and he was the one that did my assessment. And I found out he was over the Chronic Fatigue Unit. So but when I met him he was just like “Wooh”, he was just like, I suppose ‘cause, ‘cause he was about seven foot tall [laughs]. And I don’t name ‘cause he was like a Consultant Psychiatrist as well, ‘cause I’ve got a thing about, erm (2), like status as well. And although like I talk to people, Consultant Psychiatrists in my job, I can talk to them as an equal, but as soon as I walked into like him, it was just like “Who,” ‘cause I suppose it was about myself.
Interview Conducted on Friday 1st April 2005 with one participant.

And I did find him quite intimidating really. I was in tears and glad to leave [laughs]. Whereas like (3) I: Because of his physical appearance and status?

Helen: Just some of the things of how - his actual manner. And comments (XXX) and things that he actually said, it was, you know, there wasn’t a lot of eye contact, and, do you know what I mean? It was the (1) - so I suppose I put a bit of a barrier up. Well with [name of therapist] straight away, I just, and I suppose ‘cause like she’s petite and she’s very gently spoken, and err it all sort of affects doesn’t it?

I: So interpersonal skills and appearance are important?

Helen: He was quite opinionated as well. Some of his comments that he made were quite, “Oh okay.” Whereas [name of therapist] is sort of listening, and although she gave advice, it was sort of done more in a non-confrontational sort of, non, sort of like, judgmental way. Whereas he was like - he wasn’t critical against me - he was critical against GPs and it was just how he said things, and I was just like, “Whoops! I wouldn’t want to get on the wrong side of you.” [Laughs.] I’m sure he’s a very clever man and whatever but [laughs].
I: Okay. I'm just aware of the time; we have been talking for an hour.

Helen: Is that an hour! It's just flown by [laughs].

I: Is there anything that you can think of [name of assistant researcher] that we have not covered?

Helen: There was one thing that I would be interested in exploring what you thought. It was something you said a while ago, you said that you have a lot of self-awareness of how your qualities have influenced the type of career you have. I wondered about how you felt about seeing someone therapeutically given that you are a trained Counsellor yourself - sort of sitting on the other side.

Helen: Yeah, it is really really strange being - 'cause like I say working for the same Trust as well I know it's [name of speciality]. But being a patient it is really really (2) it's really different, it's just - I don't know, 'cause I don't want to be the patient [laughs]. I don't want to be the one that (2) obviously I want rescuing but obviously I don't want to be in that position where I need to be rescued. Do you know what I mean? (I: Mmm.) And to have like all this like the tables turned - is really sort of like quite unnerving. I feel quite
insecure about it because (2) it's easier to talk about

somebody else's problems than putting yourself under the

microscope and sorting yourself out. Erm, because when you

are doing it in a professional capacity you go home at the end

of the day, you're away from it. I go home and I take it with

me still and it's, it's, you know, you don't switch off from it.

It is really strange. I can't really put it into words but it has

been really really strange. Particularly like talking to [name

of consultant psychiatrist], it was just, I'm so used to talking

to psychiatrists - you know, I do it most weeks in my job and

I have all my information there and suddenly because it was

about me - I couldn't - it's that confrontational thing again.

In my professional capacity I will stand up and I will XXX to

a psychiatrist and say that they need this, this and this.

Whereas when he turned round and said something to me I'm

like, "Yeah okay." [Laughs.] Which is really (3) you know

it's like a power difference I suppose. I feel more equal when

I'm on professional terms, but as a patient I felt very much,

sort of, you know quite low and they're the professional to be

looked up too, like I suppose I did with my dad.

I: Yes mmm. (2) I was thinking along the same lines. When

you think about how you felt let down in your job, well you

strike me as a person who would go all out to help another

person...
Helen: Absolutely yeah, I will stand up for them and I’d  
have all my reasoning and I wouldn’t back down. But myself  
- I just back down. You know, I can’t stick up for myself -  
which is a bit weird.

I: But also it didn’t sound like anyone did that in return - it  
didn’t sound like anyone stuck up for you.

Helen: No not all. Nobody no - at work nobody did, it was  
just I don’t know (2). It was like, “Yes Helen you are in a  
stressful situation, okay, but we’re not going to do anything  
to help you.” They knew I was stressed they knew what was  
going on but nothing was actually done at that particular time  
to help me. Which I think there’s a lot goes on, that goes on  
a lot our job. And also a lot of the people I work with - a lot  
of them wouldn’t admit that they were stressed anyhow -  
’cause they see it as a weakness, and the fact that I did was  
like, “Oh I don’t care if I’m weaker than those, I’m stressed!”

I: So that takes a lot of guts to say that, especially when you  
knew that others might judge you.

Helen: Well I was really at the point where I knew  
something had to happen - otherwise I was going to be ill,
1008 and I was as it was! But, you know I was hoping that
1009 something was going to happen. It did take me a while
1010 before I would actually say I was stressed and needed some
1011 help but (3). I just feel let down because when I finally find
1012 that courage to say it and I didn’t get anything back, and so
1013 it’s like, well what’s it going to be like when I go back to
1014 work then! You know am I going to be in that situation again
1015 and not get any help and support? I want that for all of us as
1016 a team and not just me necessarily as an individual, for, for us
1017 all to have that, ‘cause I know that the whole team is stressed.
1018
1019 I: Yes and people think differently when they are stressed
1020 because I guess it may be like what you said earlier, people
1021 are just trying to get through the day. So some team support
1022 sounds good.
1023
1024 **Helen:** Yeah and last year work came home with me. It
1025 came home and it was with me, those feelings and emotions
1026 from work were at home with me all the time. And that’s
1027 how come I knew what it was like - you know, before you
1028 can get stressed you go home and still get some relief from it.
1029 But I wasn’t getting any relief even when I was at home. It
1030 was just there all the time.
Interview Conducted on Friday 1st April 2005 with one participant.

I: Right so the boundaries got blurred and things spilt.

(Helen: Yes.) Okay, is there anything else you would like to say that you feel is important?

Helen: Well when - sort of like looking at services, we have just like talked about the actual Chronic Fatigue Unit. But if you take it a bit further back, was erm, problems with my GP. Erm, I mean like [name of therapist] was saying that hope to educate the GPs a bit more. But I have to change my GP within the practice - because of the attitude of the first GP was obviously “It’s all in your head”, and you know (2), “you’re stressed from work, go back to work and if you’re still stressed you’re in the wrong job!” And it was like, he wouldn’t even do blood tests or anything for three months [laughs]. So erm (2) and it was, and then I saw the erm, Occupational Health Doctor, and it was like, “Well, you’re depressed.” ‘Cause I’ve had post-natal depression, “You’re depressed.” And it was only cause I changed my GP within the practice who had experienced Chronic Fatigue patients before, and then had referred people to the Unit, that she like said, “Yeah well I think something’s going on here.” And after six months I said, “Well you know what’s my diagnosis?” She said, “Do you think you’ve got ME?” And I said, “Well yeah I’m convinced that I have,” and she said, “Well there’s your diagnosis.” So I felt a bit cheated, I
almost wanted them to do loads and loads of blood tests and say, "No its not it's something else, and here's a tablet and you're going to be better!" But it didn’t, and I felt that first six months it was just a battle just getting recognised through the GP and Occupational Health Doctor. Erm, I mean the Occupational Health Doctor was from Psychiatry anyhow, so it was all (2) that approach. So, I think the initial service before you actually get to the Chronic Fatigue Unit is just a bit (3) you know (2) is not necessarily good. And I was fortunate that I did find a GP. In lots of ways I have been lucky compared to a lot of people I should imagine. But I ended up seeing a GP that, after three or four months that knew about Chronic Fatigue and believed me! And that I worked within the service so I got prioritised for the Chronic Fatigue Unit.

I: Yes it does seem like a lottery in regard to peoples’ experiences with GPs concerning diagnosis and treatment. I hadn’t asked you too much about your experiences with your GP as a lot of the other participants have spoken about their experiences and wanted to explore other themes in more depth with you. So in a way your experience is not unusual. I think it must be very difficult when you're in a job where other people are not behaving the way you feel you would behave in their position - and they go to the medical
profession for support and get disbelieved and dismissed.
But again you stood up for yourself and changed your GP.

Helen: Well in the end my Occupational Health Doctor knew it was, 'cause he kept saying that I was depressed, and I was adamant that I was not going to be labelled as depressed 'cause I knew that it was something more than that. But he then in the end wrote to my GP and said, you know that I was really experienced in physical, you know illnesses. And you know, could they take that on board and support me. As that letter was going I changed over GPs in the practice - 'cause at our Practice you just go and see whichever GP you want. So I just went and saw a different GP, and just sort of said that I hadn’t been happy with the previous GP, and that I wanted to be taken seriously. And for ten minutes she just sat there and listened to me, and I felt well this is good, because she’s actually listening to me. And even though initially she didn’t do anything - it was another three months before she put the referral in - I did feel that at least I was listened to and wasn’t just fobbed off. You know, with, "It’s all in your head," or, "Go and give up your job," or, "You can’t deal with stress," or whatever. It was, it was just again a whole different approach.
I: Yes it seems that you have had some fairly dismissive comments made to you. I know that [name of therapist] is planning to do a talk to GPs and let’s hope that increases awareness of Chronic Fatigue. (Helen: Yes it’s much needed.) So you said that the last time you saw [name of therapist] she gave you some activity forms to complete. How is that going?

Helen: [laughs] Well in my job I am always throwing out charts saying, “Fill these in.”

I: So what’s that like?

Helen: It’s like I’m never going to ask them to do it again! [laughs with researchers].

I: What impact has this experience had on your career as a nurse?

Helen: I think it has changed - well first of all I said earlier about it how it has changed how I look at my job - I mean my job was my be all and end all. Now it’s a job I will go and do and come home. But erm, and try not to be the rescuer the same (2) that I’ve always done and I suppose accept my limitations a little bit more - I can’t go in and (2) you know,
wave this magic wand that we would all love to have and make everything better. I think I’m just going to have to take on board, you know, that I have been this patient in the last twelve months and gone through so I think it will make me think about what service I’m giving. Like you were saying, about like the therapeutic relationship - like I’ve got with [name of therapist] is good. But I suppose it’s going to make me a bit more like - although I was aware because of the counselling - it’s probably made me a little bit more aware when I am dealing with my clients and their families. Perhaps I am going to be, you know, a bit more open, you know, and try and create more of a therapeutic relationships. Rather than going in and saying “Here’s your forms,” and [laughs] you know, perhaps change my approach a little.

I: That sounds really good - although I guess it can be difficult to do that as a time-pressured Community Nurse with a big caseload. But it seems that from your training and experience you really know the importance of being listened to and understood and accepted.

Helen: Yeah. And I thought about when I go back to work – ‘cause like I was friends with everybody in the office. And I think I’m going to have to take a back step from all the political stuff going on in the office and just, you know, just
stick to what I’m doing, do you know what I mean? Don’t get involved with everybody else’s lives [laughs] and what problems they’ve got going on in their work or whatever! It’s, you know, I, ‘cause I try and rescue the staff as well, you know, if they are having a stressful time - particularly junior staff, I’m like, “Well I’ll do that for you and (2).” You know I’ve got to just, you know, be a bit different when I go back to work. And not be this rescuer who has got the magic wand! [Laughs.] That’s going to be able to put everything right, ‘cause I can’t do it, I’m not that wonderful person. [Laughs.] But that’s being more realistic, I don’t mean I can’t be wonderful. (I: Yes.) You know it’s just unrealistic - I can’t be that magical person that - because nobody can be! And I think I’ve got to perhaps learn my expectations a little bit - for my sanity I think! [Laughs.]

I: Well I guess it’s about keeping yourself safe. (Helen: Yes.) And that is another boundary to be aware of I suppose. As you said earlier, one of the factors of becoming ill was when the boundaries blurred. (Helen: Yes.) But now you are aware of that - but I guess these things are easier said than done!

Helen: That’s right! And I think, you know, if I go back to work and I bet in another six months it’s just going to be the
same. I'm going to be like, you know at [name of team member]'s beck and call and everything. But you know, I've really, you know, I've really got to sort of like hold myself back this time. I've really got to (2) you know, make the changes, not say I will and leave it, I've really got to make the changes this time. Because I don't want to go through the last twelve months again. You know I don't want to sort of have ME for years and years and whatever. I will just be - keep sane!

I: And take care of yourself.

Helen: Well yeah. 'Cause the impact that it has had on the family and things that we can and can't do you know, I don't want them to, you know, to keep putting my family through that. You know, you have to have a quality of life somewhere [laughs]. Not just in front of the telly with the chocolate [laughs].

I: Although that can be quite good too! [Both laugh.]
Helen: Yes I'm fine. I feel like I have just gone on and on.

[Laughs.]

I'm glad that you have been able to be so open - I've found it very valuable. Thank you for coming. (Helen: Thank you.)