

**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's¹ convention.

Transcription Convention	
()	Pause
(2)	Two second pause (number indicates duration)
xxx	Untranscribable
(xxx)	Indistinct/doubtful transcription
...	Interruption of speech and/or talking over another person
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	

¹ Burman, E. (1994). Interviewing. In P. Banister, E. Burman, I. Parker, M. Taylor, & C. Tindall (Eds.), *Qualitative methods in psychology: A research guide* (pp. 49-71). Buckingham: Open University Press.

**Focus Group 1: 4th March 2005 at 2.00pm.
4 Participants from Waiting List for the CFS Service**

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

11

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

13

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

22

23 **Steven:** Or I guess another option would be that if you
24 produce a short summary. A written summary, that might be
25 easier instead of trying to get everyone together again.

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26 **I:** Yes and it is quite a way for some people to travel.

27

28 **Steven:** Of course do what you think is best. It depends on

29 what other people want.

30

31 **Jessica:** I don't know, I would also like the chance to meet a

32 couple of people who have also got ME. (1) Well, I am also

33 not travelling 20 plus miles, I think that makes a big

34 difference myself.

35

36 **I:** Well what I think I will do, is produce a short report and

37 then contact people to see if they would want to come to a

38 presentation, so at least you have the option.

39

40 **Tom:** When you have got all the information you want, what

41 is the overall goal? (1) What is it supposed to do?

42

43 **I:** The idea of the kind of analysis I am doing, is that you get

44 a theoretical model that is based/grounded on the information

45 that is generated in group discussions.

46

47 **Tom:** And that's supposed to help health professionals,

48 doctors etc?

49

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50 I: Yes I will be feeding back to the CFS Service. I will also
51 be looking at publishing the research in a peer review journal.

52

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

55

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

67 [All members nodded in agreement]

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

73 [Consent forms handed out and pens given to each member]

74

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75 **Jessica:** Was the Information Form the thing that you sent
76 out to us?

77

78 **I:** Yes.

79 [(34) The group members completed the form]

80

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

84

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

87

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

90

91 **Julie:** I normally refer to it as CFS.

92

93 **Tom:** Yes I know it as CFS.

94

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

97

98 **I:** I usually say chronic fatigue I am a bit lazy and don't use
99 syndrome. [Laughing]

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100 **I:** Okay. A good place to start is to think about how would
101 you describe CFS to a person who did not know what it was?

102

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

113

114 **Julie:** At least it shows she understands.

115

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

118

119 **Julie:** I use flu.

120

121 **Tom:** Yes I use flu.

122

123 **Julie:** Because I have never had glandular fever.

124

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125 **Tom:** Yes it's just like the onset of flu, but it's there all the
126 time. (I: Right)

127

128 **Julie:** Because that is what I thought I had to begin with. It's
129 like you ache all over all the time. Whatever you are doing
130 you know if you are able to lie down comfortably. (I: Right).
131 Whatever the time of day or night, given the opportunity I
132 will be able to sleep.

133

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

137

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

144

145 **Julie:** short attention span

146

147 **Tom:** problems of words ...

148

149 **Julie:** Yes I struggle to get my words out...

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150 **Steven:** ehm problem with finding words. It's the cognitive
151 side which is, ehm, more ehm (2)

152

153 **Jessica:** Troublesome?

154

155 **Steven:** Yes more troublesome but also the side, which
156 perhaps is hard for people to get a handle on because yuppie
157 flu you know is... [Tom laughs]. It's just people are tired,
158 you know and so you forget there is a whole range of other
159 things. The pain, the pain discomfort side is also, something
160 which is- I am fairly fortunate I am not in severe pain but I
161 know some people with this condition, who are dosed-up on
162 pain killers all the time because of muscle pain and joint pain
163 or a combination of the two. So that is, that can be a
164 significant part of the syndrome for some people.

165

166 **Jessica:** I think the thing I find really, it's, when you are
167 talking about the cognitive stuff - is when you like you have
168 forgotten where your keys are for the tenth time that day and
169 you are going, I can't find them, I can't find them and I get a
170 bit stressed these days about it. (**Tom:** Yes, yes). Because it
171 kind of makes me feel sick, because of the number of times I
172 have spent half an hour looking for my keys when they are
173 exactly where I put them and I can't see them when I look at
174 them sometimes. And people are like, oh yes that happens to

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175 me all the time and you are like no, no no, there is a
176 difference between it happening once a week or once in a
177 while to this many times a day and people don't get when
178 you start to get stressed, or when you are struggling to find
179 the right word, and they just think well everyone struggles to
180 find the right word occasionally. (I: right). But when it's
181 like, all the time...

182

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

187 [Jessica laughs in agreement]. Someone could ring and ask
188 me a question and I would have the answer. Now I'm having
189 to say I have got to go away and look it up. (I: right) And I
190 am having, I could read things and that's it I'd got it but now
191 I'm having to read and re-read and highlight it and make
192 notes and (2) you know these things- for somebody who asks
193 what's the problem. Yes I'd explain the physical side
194 because that's the easiest thing for them to understand. (I:
195 ehm, yes). The other side, yes if they hadn't known me
196 before they wouldn't know there was a problem (2) but I
197 know that there's a cognitive problem there and people that
198 knew me well before, know there's a problem there. (I: Yes).

199

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200 **Jessica:** Yes – one thing is there are some symptoms I don't
201 feel comfortable telling other people about I don't mind
202 chatting to my other friends about it who have got ME about
203 it. But one thing I used to get, well I still do to some point is
204 that my bowels are not under my control any more [she
205 laughs] so I can have constipation and the next second like
206 that diarrhoea. Well if I am feeling like that, and my lecture
207 isn't, wasn't near the toilets it would be like well I can go to
208 the lecture and risk shitting myself [laughing] or I can skive
209 the lecture and stay near my toilet. And frankly the toilet
210 seemed more important. And it is like when tutors go well
211 why were you not here, it's like well who would really fancy
212 sitting there next to me, pooping myself [she laughs, then all
213 participants laugh]. You know it's, it's kind of, it's just
214 there's so many different things. I mean one of the problems
215 I've had, this is a slight digression is that I have actually had
216 another very serious illness. And they didn't know I had a
217 brain tumour simply because ME has so many symptoms, I
218 mean just about every symptom in the world seems to be part
219 of ME. But they didn't notice it coming until I was laid up in
220 bed hallucinating and unable to walk straight. It, you know
221 was literally last minute, "oops", [laughs], "better get her into
222 surgery now". It's just like, you can't go to the doctor every
223 time you develop a new symptom. I feel like I see my doctor
224 plenty. I mean I'm sure he is fed up with the sight of me

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225 [laughs]. But what do I do, I mean I now know, don't know
226 what to tell the doctor and what not to, because when I started
227 seeing things it's like well yeah there was a cat wandering
228 around my bedroom there was an alien hovering in my, you
229 know hallway in the night. That's not unusual that's been
230 happening for 10 years. So, I you know, and the doctor was
231 like, "Well if you'd said that I would have been worrying".
232 And that like, but it's been around for, you know what I
233 mean?

234

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

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250 [Laughs].... (Tom: I, I...) [Finishes laughing]. Sorry go on.

251

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

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275 treating these symptoms and in the end I thought, well I will
276 just live though it and find ways of just accepting what's
277 there.

278

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

288

289 **Steven:** Well, let's be honest about it there's an also an issue
290 of personality here. It is known that ehm that people who get
291 this condition tend to be more control freaks than perhaps
292 people who don't. It doesn't mean that it's a psychological
293 condition, it just means that we tend to be people who are
294 perfectionists and people who are used to being in control of
295 our own lives. So, this kind of condition is very difficult to
296 cope with because of that- because it takes away that degree
297 of control that you have so you are caught up in trying to sort
298 of go on as business as usual. Whereas the reality is your
299 body is not allowing you to do that.

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300

301 **Jessica:** But you can't trust your own senses. You know I
302 was going through this thing when nothing tasted right.
303 When I have had Tinnitus, I have been like in the night
304 going, "Ooh is that my alarm clock!" Cause it beeped, you
305 know I was using my phone and I was hearing ringing
306 beeping in my ears and I wasn't sure if that was the Tinnitus,
307 sort of thing, so I would wake up pull the ear plugs out and
308 go Nope level hasn't changed must be Tinnitus then, you
309 know [Tom & Steven agree] which disturbs your sleep erm,
310 when you are seeing stuff, you think the cat's out, but you
311 keep seeing this black thing out of the corner of your eyes
312 fluttering around and it's just like it gets to the point where
313 you know, I have been at crossings, seen the light change,
314 stepped out to have drivers swear at me because the lights
315 haven't changed, and I step back and the next time it's
316 changed there has been a light and a noise and you are like,
317 shit okay, and it makes crossing, you know, it comes to
318 something when even crossing the road you can't be sure,
319 you just can't! And It's, (2) I don't have words for it, I can't
320 explain this to anybody. You know its like

321

322 **I:** I think actually from what you have all said, flu doesn't
323 seem to touch it now really...

324

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325 **Julie:** No, flu is (2) it's the physical feelings.
326
327 **Tom:** Yes it's the physical
328
329 **Julie:** There is so much more. When I finally erupted in front
330 of my doctor, well this isn't the only symptom, this is
331 happening, this is happening, this is happening and I finished
332 with I am increasingly getting bad hangovers on an ever
333 decreasing amount of alcohol. [And everyone laughs].
334 (**Steven:** Yes, yes).
335
336 **Tom:** I think the confidence thing is, erm, I expected it to
337 have like, when it first happened it was like flu, couple of
338 weeks off work I'll be alright. But when it went on and on,
339 the first time you encounter someone who doesn't believe
340 you, erm or maybe its in your own mind you know that,
341 someone thinks you are making more of a meal of it, that's
342 when my confidence got knocked. (I: Right). And
343 unfortunately it was close to home because my wife at the
344 time hadn't been having a good time so when you feel
345 doubted you begin to think well am I making more of a meal
346 of it. And then you go through, I think my first lucid spot as I
347 call it was like, I was back to normal, I woke up, my energy
348 was back so I started doing things like normal, big mistake
349 [laughs]. 'Cause you know that day later I paid for it and paid

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350 for it about a week or so. You know I really went back to
351 really heavy symptoms. Erm, so that was like something I
352 had to deal with, and it was almost as bad as the stuff itself,
353 as it was, explaining to people actually no I know this is
354 going on a long time but I am not putting it on and I don't
355 have the control over it that I would like. Then having to be,
356 I mean sometimes I've been from my way seeing of it pretty
357 bloody minded because I just think "no I've got to set some
358 parameters where I operate- and if people think I'm being
359 selfish its tough because if I go beyond them too much down
360 I go".

361

362 **I:** So it's a learning curve? (**Tom:** Yeah).

363

364 **Jessica:** I'm much more careful with friends now as well I
365 mean for me its been a long time I was diagnosed in 1991,
366 and in that time I have had friends, who you know, when I
367 have been managing it well, I get, I know that I could go
368 away for the weekend and as long as I sleep really well I can
369 be a bit stupid and then for the next week or two I will be
370 very tired, very in pain and everything will be up the creek.
371 And then she would go around telling people "I know she's
372 all right because I've seen her". [Group agreement] forgetting
373 that you know that if I'm feeling really ill you don't see me
374 because I can't cope with that I can't cope with somebody in

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375 the house. If just the slightest noise reverberates around my
376 head and feels like lots of people not, and you get confused
377 by more than one noise at the same time. You know,
378 sometimes friends will be like, "Oooo I'll have music on",
379 while we chat and I'll be like, "No please don't". (Tom: Do
380 you get...).

381

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

385

386 **Tom:** Do you get noise sensitive? (**Jessica:** Sometimes
387 yes). And light sensitive as well? (**Jessica:** Yes, yes). I
388 sometimes think, well I turned 50 last year and I think I've
389 got to try and sort out what is natural aging and my own
390 predisposition as well. I have never had kids but sometimes
391 I'll be out and like if there is a kid screaming I can just feel
392 like, "ahh just somebody take them away". Then I think,
393 "I'm overreacting here- just get a grip"- and then I remember
394 sitting in the doctors waiting room, and everything seemed
395 amplified, it's like what you said, its like having a bad
396 hangover but, I am a very moderate drinker you know, I can't
397 drink more than a glass of wine anyway. It was like I
398 remember from years and years ago having a real heavy
399 hangover, my head was throbbing I couldn't take noise my

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400 wife would put a cup down, and I would just sort of cringe
401 [holding his head in his hands and everyone laughed]. As a
402 bloke, I don't know whether you sympathise with this (looks
403 at Steven), perhaps its more so than with women, but your
404 own ego kicks in, you want to get a grip you want to do
405 something and just get on and do it. But then you feel
406 defeated. (Steven nods)

407

408 **I:** I am interested...

409

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

412

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

414

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

423

424 **Tom:** Yeah I found that. (**I:** Right).

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425

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

436

437 **Julie:** Yes being bombarded with too much at once, you
438 can't take anything in.

439

440 **Jessica:** It was like my brain was shutting down because it
441 was too much & then it wasn't too much any more. So I think
442 my energy levels were lower but they weren't (2) I wasn't
443 like wanting to shut down and just fall down and crawl under
444 the duvet [laughs] but being under the duvet is quite a nice
445 place to be sometimes but I also, I mean a lot of people I
446 know love the idea of a lie-in. If I am not feeling really
447 knackered I hate lying in bed now. It's like being put in
448 prison and I used to love that, you know Sunday morning,
449 have an extra lie-in have an extra hour or two, you know

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450 maybe read the paper in bed or a book or- and now it's just,
451 (2). Well maybe it's just me, but that feels like just being in
452 prison, it's not the place I want to be. (I: Right). I feel kind
453 of jealous, not jealous not happy- but you know the joy of
454 lazing about in bed has been stolen from me [laughs].

455

456 I: Because resting has a different meaning?

457

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

463

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

468

469 **Jessica:** I find I vassellate between sometimes I want to do
470 stuff I haven't been able to do stuff for ages I want to do
471 stuff. And then I get to this point where I am terrified to
472 exercise 'cause that's the thing that will make me ill. (Tom:
473 Yes). And it's very hard, I mean what you really need to be
474 is rational about how much you can and can't do. (Tom:

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475 That's right). And the thing is it doesn't stay the same any
476 way, one week you can walk into town okay and the next
477 week you know maybe you can walk to the corner shop,
478 maybe. You know it doesn't stay the same and your feelings
479 about it don't stay the same and they don't stay in line with
480 each other. So some days you should be doing more to be,
481 you know because I, I I tend to think you should be doing as
482 much as you can without knackered yourself, otherwise you
483 just go down hill.

484

485 **Tom:** hmm, you just accept this

486

487 **I:** So when you feel that when you physically can do
488 something you do it and when you don't...

489

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

496

497 **Julie:** Well, the advice I got most often is pacing. You can't
498 do loads when you feel better and nothing when you feel bad
499 because you will be just be boom and bust it's about trying to

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500 do a set amount each day. Well I work (2). So it's difficult
501 Monday to Friday to do anything else except work. So when
502 I have weeks where I have to travel to meetings in Croydon
503 and London which means early starts and late getting back I
504 know, whatever the thing they say about pacing, I know I
505 don't want to be doing much that weekend because I am
506 going to be tired. (I: Right). And the upshot was last
507 Saturday I got out of bed at half past five in the afternoon.
508 Because I kept sitting up and thinking, "my headaches and I
509 will just lay here for another ten minutes", and that would be
510 it, I would be gone again for 2 hours. So the pacing actually
511 goes out of the window because there are, I have to do more
512 on some days, it's a reality. It's just the reality of the
513 situation, so some days I do just have to do nothing to make
514 up for it.

515

516 **Jessica:** You have just hit the nail on the head for me. I have
517 got to the point where I keep an energy diary and every day
518 I've divided it into hours, so when I rest it's a plus 1 and
519 when I do stuff that isn't really tiring but it's not resting
520 either it's a zero and when I do anything it's a plus 1. (I:
521 Right). You know, and it has to come to a certain figure.
522 But the problem is that I know, for example, when I am
523 having my period I am more knackered. It's just a fact of my
524 life. That I can manage until the landlord decides to paint the

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525 flat and then I have to move stuff and everything stinks and
526 then I can't sleep properly because of the smell next thing I
527 know I've got a relapse on my hands because you can't
528 control life. You know shit happens I suppose. I am using
529 awful language [laughs].

530

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

535

536 Steven: You go into the boom and bust scenario- because
537 you say to yourself I, I, I'm more than this, you know I can
538 cope with this, I can recover. But the problem is, you are
539 back to, you need to be very disciplined in order to say, "No I
540 shouldn't be doing these things and/ or I should be very
541 careful about monitoring the level of activity". With the way
542 I do it, is at the moment I am fortunate because I have not got
543 a huge amount of external pressure- so I don't have, I am not
544 working at the moment I am not unable to work- so for me
545 what I have to do is to say, "Okay I will try and do a minimal
546 level of activity which will also take me out of the house, to
547 try", and, part of the argument is that natural sunlight is
548 essential for boosting your immune system. (I: Right). And
549 maintaining activities is essential for keeping your immune

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550 system working as well. So it is incredibly difficult. And
551 that's why when you look at other people when you read the
552 sort of articles that say we'll tell you how or what you should
553 be doing, you've got to say okay well this is an idealised
554 scenario but in reality you have got to live your life and you
555 have got to do the every day things that people have to do.

556

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

567

568 **I:** So there's a knock on effect?

569

570 **Tom:** Yeah yeah. I mean my wife works, I'm not working at
571 the moment. So I've taken over all the domestic duties, but
572 sometimes she'll come home and I've not done much, and I
573 just say "look don't worry about it, I just couldn't manage
574 much today". Erm, but I've had to do that cause I thought

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575 otherwise, you know; I'll end up doing nothing and
576 compound the problem. (I: Right). Errr...

577

578 I: So there's something about balance?

579

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

589

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

593

594 **Tom:** Well that's my personal experience.

595

596 **Steven:** One suspects that one of the reasons you got where
597 you are, is also the fact that, as a personality type, I would not
598 listen to my body telling me not to do things, and it's caught
599 up with me. You know, over a period of years, I've pushed

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600 my, errr, stress levels up, you know like adrenal burnout- I
601 think is probably a fair way to describe that, but it doesn't
602 mean, it doesn't mean that I haven't got a physical disease or
603 a physical condition. It just means that my personality and
604 also possibly genetics has predisposed me to getting this.

605

606 **Jessica:** It's interesting actually, a friend of mine's got
607 Fibromyalgia, which may or may not be the same thing as
608 ME, but with different things presenting as, more stronger
609 symptoms...

610

611 **Tom:** It's more joints isn't it?

612

613 **Jessica:** It's muscle pain and stuff, but actually her and
614 another friend of mine have both had it, and it's so similar
615 that it's beyond belief. But she's actually studied to be a
616 dancer, and erm, we were both talking that, you know when
617 we were fifteen/sixteen, we were both doing a hell of a lot. I
618 mean, burning the candle at both ends didn't come into it. I
619 just didn't need sleep much. Which people never believe
620 about me now. [laughs] But hey! And we both sort of said
621 that have you ever wondered if, because you used to be like
622 this when you were young, you've kind of scuppered yourself
623 now? It's like is it because I overdid it as a kid? (I: Right?)
624 Because I took for granted the fact that I could do so much,

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625 and I did do so much. I don't know if that's just feeling like
626 in someway you've got to have a reason that you're paying
627 for this now. Or whether it's a real concern?

628

629 **I:** I understand what you mean.

630

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

638

639 **Tom:** But could that lifestyle, irrespective of your age, erm,
640 it's like Steven said, if you're sort of just ignoring everything,
641 and just pushing yourself, and that's a natural way for you to
642 do things, then nature steps in, it seems you have to reassess
643 how you've lived, whether it stems back to your teens or
644 later. (**Jessica:** Yeah). You know, 'cause if you work hard,
645 and everything is work, and then there's deadlines to meet, or
646 whatever your priorities are, I don't think, in fact I never have
647 thought that you can carry on like that, life's too out of
648 balance. But it seems that, as I look back, I somehow missed
649 that message for myself, you know [Tom smiles, Steven

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650 laughs], so I got caught out with it. I mean I know for two
651 years I worked absolutely flat out. (I: Right). And I did
652 ignore all the things that I would have told someone in my
653 place not to ignore. You know like, catching colds a bit more
654 often, and feeling tired, but ignoring, getting up really early
655 and not worrying if I didn't get enough sleep. I can look
656 back now and say, "Well actually I was doing all of those
657 things". And I was setting myself up. (Steven: yeah). So
658 it's not so much a mystery, I mean previous to that, life
659 hadn't been too demanding.

660

661 **Jessica:** Yeah but theory and practice are different though.
662 It's bloody easy to get theory, but getting practice into your
663 life is different.

664

665 **Steven:** Yeah [laughs]. I think that, just before I forget, I
666 mean what you've said, sort of strikes a chord with me. One
667 of the things which I think is interesting, is that, that, in all
668 the time that I've been seeing my GP with a variety of
669 problems that are showing that my body is running into
670 overload. Erm, so we're talking about years; so we're talking
671 about IBS; we're talking about fatigue; we're talking about
672 upper respiratory infections, all the sorts of indications that
673 your immune system is struggling. Erm, in no time during all
674 that, during the time I saw my GP, was it ever suggested that

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675 my lifestyle might be a problem. That actually you're not
676 doing your body any good! What you need to consider is, in
677 general terms is, look at your diet, look at your lifestyle, and
678 there's no preventative- I think that's one of the failings that
679 we have in terms of our medical services, there's no emphasis
680 on preventative care. It's also treating acute rather than
681 chronic than chronic conditions, so if you go to your doctor,
682 and you've got an upper respiratory infection, the chances are
683 he's going to give you an antibiotic. (I: Mmm). You know
684 he's not going to, he's not, even if they are recurrent, erm,
685 that's likely what you're going to be offered. Rather than
686 looking at the whole picture and saying, "Well what's
687 happening in this person's life?" Are they (2) well I think
688 that's a factor in these chronic conditions becoming
689 debilitating.

690

691 **Jessica:** Can I ask a question? What advice were people,
692 when you were first diagnosed, when the doctor first said or
693 when you said to the doctor I suppose, "There's something
694 seriously wrong", and they said "Well it might be something
695 along the lines of chronic fatigue". Did the doctor say
696 anything to you advice-wise? Or what?

697

698 **Julie:** My GP said erm, "There's not very much known
699 about it, because there's been a lot of studies, none of them

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700 large scale, the Government has just commissioned a large
701 scale detailed investigation. But the thing that has come out,
702 the common theme amongst all the small scale projects that
703 has been done at the moment, is that pacing yourself is the
704 best thing to do". And just because there were various
705 physical symptoms, she was doing the tests one by one to
706 discount everything else that could cause them. And it was,
707 "I will refer you to the Chronic Fatigue Service", and I'm still
708 waiting for my first assessment with them, nine months on,
709 so I'm not overly chuffed. (I: Right).

710

711 **Jessica:** Well that's truthful [laughs with Steven] (**Julie:**
712 And err...).

713

714 **Tom:** It was nearer last August mine. No, last June was
715 mine, well that's the time it was mentioned.

716

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

722

723 **I:** Right. So there was something about the name bringing it
724 together.

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725

726 **Julie:** Well there was part relief at knowing now that there
727 was this term that covered all these things. (2) But there was
728 also despair in that I knew I couldn't get a tablet and take a
729 course of treatment, and I would be better in a month. And I
730 knew this could take years, or it could take the rest of my life.
731 So there was all that uncertainty there 'cause my GP basically
732 fessed up straight away "We don't know what causes it, so
733 we don't know how to treat it".

734

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

737

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

740

741 **Tom:** My doctor said basically the same. She said, "Well
742 probably it's chronic fatigue syndrome", she said, "But
743 there's not much I can do about it". She said, "A lot of it
744 rests with you and how you adapt to it and how long it lasts".
745 And of course I'd been looking at websites anyway, and my
746 wife's an assistant manager in a doctor's practice, so I was
747 getting a mix of information from her. (I: Right). I think
748 one of my lowest moments was that a friend of err one of the
749 staff, a doctor, had ME, and it had lasted seven years. At that

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750 point, I mean this was in the middle of last year, and I was
751 feeling particularly rough and I thought “Oooh”, because it
752 was bearing out stuff on the website. You know, they say
753 some people recover within two years fully, some people get
754 about eighty per cent of their health back but it takes up to
755 about five years, and some people don’t recover. Erm, it’s
756 just there for just years and years and years. And I just
757 thought “oh”. [Laughs]. You know.

758

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

762

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

767

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

771

772 **Tom:** Well I suppose part of me didn’t want to, well still,
773 three or four months into it I really wasn’t convinced it was
774 going to be that bad. I was off work but I was still employed.

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775 And I kind of half-convinced myself, yeah it's just a matter
776 of time and I'll be all right. And then Jenny came home and
777 told me about this person who had been, by all accounts
778 much more active in the world than I had, you know, I mean
779 she, but when she said, you know, she'd still got it after seven
780 years and she's only just started to feel right, I just thought,
781 "Errrrr". You know, and it would be at that point very easy
782 to get disheartened, erm and I did go through a bit of a
783 trough. But I picked up and thought, "Well, I'd have to
784 manage it all myself and not keep looking as to what the
785 future may hold, but just be more immediate". You know,
786 sort of, again starting to take the advice that I would have at
787 one time said to someone, you know, "Don't worry about the
788 future deal with how you feel now, and build on that and
789 know what your limits are".

790

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

793

794 **Tom:** Well I suppose I was lucky 'cause I was resurrecting
795 old disciplines. You know, years ago I used to be involved in
796 yoga, meditation and stuff. So I had a bit of a background to
797 draw on it, but it was a kind of, when you feel low, you don't
798 feel like doing it! [Laughs with Steven and Jessica]. I'd go
799 through these inner fights like you know, like, "Am I being

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800 mentally lazy here? I know better than this!" But some days
801 I have to sit down and think, "Look you just can't do it today,
802 and that's all there is to it". (2) But equally the other way, I
803 knew when I was making excuses for myself, so it's been a
804 real kind of learning curve. [4]

805

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

809

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

819

820 **Julie:** It's really about accepting that this is your new
821 reality...

822

823 **Steven:** And you've just got to let it wash over you and
824 you've just got to forget your old, you know, it sounds, it's a

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

847

848 I: How are you all doing, are you okay? [All participants
849 expressing different needs e.g. having another drink, going to

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850 the lavatory, etc]. If we have a break do people want to
851 continue after? [All participants agreed]

852

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

854

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

857

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

866

867 **Jessica:** But it's this weird thing that I, I get, I'm like vaguer,
868 but then the phone rings and I'm like "erghhhh!" (**Tom:**
869 You jump, yeah). And it's just like...

870

871 **Tom:** It's a contradiction in terms.

872

873 **Jessica:** Yeah! You shouldn't be that acute to things that
874 normally make people startle, when you are vague about

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875 everything, it's like well how are you noticing everything.
876 [Steven sighs]. I just wanted to come back to something
877 Steven said just before we changed the tapes. About how you
878 kind of have to start anew it's like, the old me is not in
879 existence anymore. But when I first got ill for ages it was
880 like when I get better I will go to university. When I get
881 better I will do stuff, you know. And there suddenly came a
882 point, where I don't know what happened but I suddenly
883 realised that actually you know I, I, I trained in acting and
884 stuff and I suddenly realised that stage work was something I
885 was never going to be able to do again. (I: Right). I would
886 never, I don't know the information at the time wasn't that
887 you would get 100% better, but a lot of it was like you would
888 get better, I mean by that I mean maybe 80%. (Tom:
889 Ermmm). And I just thought well filming for about 12/13
890 hours doesn't work when you know, being up all hours and
891 all that sort of stuff, the lifestyle just isn't conducive I will
892 never be able to do it. I will never be able to do it. And I
893 went into this deep pit of mourning. (Tom: Ehmm). You
894 know, having worked all my life, it felt like, towards this
895 goal, suddenly it was like, "Oh, okay that's not happening".
896 And it literally was like being in mourning. And at the end of
897 it, I suddenly started to realise I can't put everything off until
898 I get better. Don't know when that's going to be? It might
899 next, you know, it might be six months or it might be in ten

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900 years. Now I know it might never be And somewhere along
901 that I suddenly realised actually what I needed to do was to
902 work out I can live as I am and if I get better it's gonna be a
903 bonus I'm not going to be upset about. You know, even if I
904 only make a 50% improvement then I am going to feel like
905 I'm ahead whereas before I would have felt like I've still got
906 50% to go. [Julie and Tom agree] You know, so then you
907 start looking at everything like, "Well I'm better than what I
908 was". But the problem is that then you know that most
909 people are better within five years so I was like for some
910 reason as soon as that five year anniversary came close [all
911 members laugh]. I suddenly started being extra careful about
912 everything I did because I was going to be better in a few
913 months. (I: Yes). And you know, when I wasn't I hit that
914 depression again. And then I came out of it again. And the
915 same thing happened around the tenth year anniversary,
916 except this time I thought, "hmmm I'm sure I have been here
917 before" [laughs]. But, I'm some ways I'm glad in a way that
918 all those anniversaries have passed. Because I think, if there
919 was a fifteen-year one that most people are better by, I might
920 fall into the trap of going, "Yes! This year", I'm going to
921 wake up being better and it will work because the odds are in
922 my favour". (I: Yeah, yeah). But the trick is, but every time
923 that hope's offered to me I go "No, no no- I'm not accepting
924 it, (gasps), and then I do". And it's insane. After the tumour

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925 was taken out, one of my surgeons said “Well you might find
926 that the ME has gone”. He was horrified that, you know I’d
927 been ill for like thirteen years and had never had a brain scan.
928 When a lot of my symptoms were neurological. (I: Mmm).
929 Which you know is pretty reasonable. And (2) at first I was
930 thinking, “No, no I’m not believing him”, but everybody I
931 knew heard the might as an is. She might not have ME
932 turned into she does not have ME. (I: Right). Because other
933 people are very keen to see you improve as well and suddenly
934 my dad said, “Well I never felt quite right about you having
935 ME. You know I always believed you were ill, but I didn’t
936 really believe the ME thing, it didn’t feel right”. He managed
937 to sort of put you know lack of balance and all this together,
938 to correlate with the part of my brain that was affected- so
939 that the only thing wrong with me was the tumour. And I
940 was sat there thinking, “No, no no no no!” the cognitive stuff
941 that was happening was up here in the front of the brain not at
942 the back thank you very much. (I: Right). But then...

943

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

945

946 **Jessica:** Well at the time I was a bit like blurb, but to be
947 honest I was busy buying into the, “Yeah, yeah, I don’t have
948 ME. I can go and live a proper life, I just have to kind of get
949 back on my feet from this, you know, this problem”. And

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950 then, to be honest I'd had extra fluids, during the operation,
951 they chunked me on to an IV and, I have never not felt better
952 when I have had extra fluids. But I can't find a doctor to do
953 that for me [laughs]. You know, if I have a drip I will feel
954 better for about 6 months. (I: Right). Every time, I had my
955 appendix out and the doctor, you know you are meant to feel
956 awful after you have had your appendix taken out and I was
957 like, "YESSSSS, energy. I can walk into town". Which for
958 me was fantastic, and all my friends could see it, and it
959 literally was, you know, you, you give me a week for being in
960 hospital and having me insides cut open and stuff, And yeah,
961 I was a bit bent over and stuff but I had more energy and I
962 felt better in myself. And every time I have a drip the same
963 things happened. And there actually research out there,
964 somebody called Doctor David Bow I think, has found there
965 is a lowering in the amount of blood actually in your system.
966 But if you give blood it gives a better result short term but
967 then if you try it a second time it doesn't work as well and the
968 drop will happen again. (I: Erm...) Whereas if you give
969 fluids, the initial improvement isn't so good- but it doesn't
970 deteriorate in the future, does that make sense?

971

972 **Julie:** I think so, yes.

973

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

991
992 **Steven:** Can I come, can I comment in on that? Because I
993 really think that is one of the areas where, I think there is a
994 need for service. As a service, there is real problem, in terms
995 of sifting out the wheat from the chaff. Because there is so
996 much information now on the internet..... (**Jessica:**
997 Mmmm). Some of which is clearly dubious, and some of
998 which is downright misleading. And really what you need is

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999 some intelligent filtering of that information in a digestible
1000 form that people can take on board. (**Jessica:** Yep...) So for
1001 example either, erm, an NHS endorsed website, to give
1002 advice about the condition, erm, and possibly a Helpline to
1003 give people advice over the phone or in any other way they
1004 need it as well. And I really do think that as well, because
1005 I've gone down the same route, I mean it's interesting that
1006 you should talk about, you know, fluids being added, because
1007 one of the arguments is that, erm, that the problem with this
1008 condition is, erm potassium sodium imbalance in the body. It
1009 doesn't cause the condition, but it's a possible side effect. (**I:**
1010 Right). And so certain foods might actually help you, so for
1011 example, if you eat a lot of bananas, they might actually help
1012 you because you are increasing the potassium levels.
1013
1014 **Jessica:** Yep, yes. I craved bananas when I first got ill...
1015 (**Steven:** Right...) I thought I was pregnant [laughs]
1016
1017 **Steven:** It is interesting that careful, carefully digestible
1018 advice. (**Jessica:** Yeah). By somebody that is used to sifting
1019 information. And most people, let's face it, are not used to
1020 sifting a lot of information. (**I:** Absolutely) And also this
1021 condition makes it harder for you to sift information.
1022

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1023 **Tom:** I thought the idea was for you to get that sort of, well,
1024 some information from your doctor, but they're not
1025 specialists in CFS, but there's the Specialists we've been
1026 referred to at some point, [laughs] you know, we're waiting
1027 to see, will be able to meet those criteria more. (**Jessica:** I...)
1028 It just takes so long, I mean... (**Steven:** Well hopefully!
1029 Then laughs). I said to my doctor when she said well, erm,
1030 "I'll refer you to this specialist (2) it might be a bit of a wait".
1031 The last time I saw the doctor she said, "Oh you've heard
1032 nothing yet?" and I said, "Well I'm kind of hoping by the
1033 time it comes round I won't need it". (**I:** Right). Cause I got
1034 used to it in my mind that this is going to be a long time and
1035 it's already been eight or nine months. But going back to the
1036 blood thing. I've had no end of blood tests. Erm (3), you
1037 know, I go to the hospital quite regularly. The main thing
1038 they've found when I went down with this really heavy virus
1039 before CFS was diagnosed was a low plate blood count. And
1040 erm, the Consultant I saw at the hospital when I said- when
1041 the CFS has been diagnosed- "Would the plate blood count
1042 have anything to do with it?" They were adamant "No".
1043 And I said, "Well how can you be that sure?" They just said
1044 "No". I said "Well sometimes when you have given me the
1045 readout which has been as low at ninety at one point so I have
1046 felt genuinely quite tired out but on the higher readings I've
1047 not been so bad, so to me there seems to be a correlation", but

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1048 they're adamant. (3) (Jessica: Can I be...) They've said this
1049 low platelet count is idiosyncratic to me that, you know, I
1050 seem to be living okay. They said, "Oh if it drops to about
1051 sixty or below then we'll start to worry". And I said, "Okay"
1052 [laughs] because I am not taking a load of drugs for it.
1053
1054 **Jessica:** I don't know, I mean one of the problems is that
1055 what you can't sift through stuff yourself, but relying on a
1056 doctor to do it is very difficult because the doctors I have
1057 met, some of them have been very sympathetic and some of
1058 them haven't admitted ME exists. But there's this general
1059 thing that doctors know, we know, and you're sat there
1060 thinking well if you don't know about ME, there's so much
1061 not known that how can they say when your platelet blood
1062 count isn't attached- and I keep thinking there's so many
1063 times where I can see direct links, you know I have fluids, I
1064 have a drip, I feel better always every time. But people keep
1065 saying, "Oh it's nothing", and maybe somewhere it would be
1066 nice for researcher got in contact with everyone with an ME
1067 diagnosis and says well what has worked? (**Tom:** Erm).
1068 You know, to you. (**Steven:** Yes). Nobody has done this!
1069 The other thing is there are several things out there that are
1070 possible treatments, you know, B12 injections (2) I don't
1071 know if anyone has heard of those? (**Julie:** Well, I had...) I
1072 heard about them when I first got...

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1073

1074 **Julie:** I had a low platelet count as well, which was put one
1075 of the possible causes of this is low B12. But when they
1076 tested my B12 level it was fine. (**Tom:** It was fine yeah).
1077 (**Jessica:** Yep).

1078

1079 **I:** Did you recognise as Tom did that you felt better when
1080 your platelet count was higher?

1081

1082 **Julie:** I basically feel crap all the time.

1083

1084 **Steven:** [laughing]. My blood platelet level was low as well
1085 but that, but that was in the early, that was in the very early
1086 stage, sort of like first flare-up of the condition.

1087

1088 **Julie:** Yes, this was all to do with the diagnosis. (**Steven:**
1089 My, my blood...) I applied to a new dentist recently, and you
1090 had to list all the inoculations and blood tests you had had
1091 since you were a child. And they gave you a box that big
1092 (gestures a small amount between thumb and index finger).
1093 [Laughter]. Now I like to travel, my inoculations nearly fill
1094 that. [She laughs]

1095

1096 **Jessica:** But what I was going to say was in the whole, there
1097 are some treatments out there that some people think might

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1098 work or might help is, you know, I heard about B12 when I
1099 first got ill back in, what 1991. The second GP I saw, 'cause
1100 I had to, I moved, erm basically said, "Well there is not a lot
1101 we can do for you and I feel really awful, I know you are
1102 suffering but I don't know of anything that works". And I am
1103 like, "Look this has reasonable basis can you look into it",
1104 and basically unless somebody gave you a cast iron guarantee
1105 that it would work and that it was, is it licensed? (I: Right,
1106 yes). That actually when the NHS says yes you may do this
1107 with this condition. Yes, they won't do it. [Steven sighs].
1108 But the problem is, that if nobody tries it how will it ever get
1109 licensed? (Julie: Mmmm). So there's lots of these possible
1110 treatments out there, but no GP, you know, GPs are very
1111 reluctant to try things that aren't licensed because it's on their
1112 head on the block... (Steven: Mmm). And you've kind of
1113 got this catch twenty-two...
1114
1115 **Steven:** Yeah but you're also into snake oil aren't you! Into
1116 the whole business of saying well you're trying to, you know,
1117 when people get desperate they'll try almost anything.
1118 (Julie: Yes). And you know there's a point where, where,
1119 where it just starts to be counterproductive to try anything
1120 and everything. And I think we are back to what's needed is
1121 some, a good research into, into causes. (Julie: Mmmm).
1122 First of all finding out what the hell is going on in people's

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1123 bodies. (I: Yeah). The real problem I suspect, there certainly
1124 seems to be good evidence of this is that we are not dealing
1125 with one condition. We're not, we're not dealing, the
1126 symptoms are, err, can, err, of chronic fatigue syndrome can
1127 be, err, is likely there is more than one medical condition
1128 which takes you to this end point which is called Chronic
1129 Fatigue Syndrome. Which is why some treatments seem to
1130 work well for some people- something and other things don't.
1131 I mean for example, the antidepressant Sertraline seems to
1132 work well for some people with ME. Other people it does
1133 nothing for. And likewise, some people say, for pain for joint
1134 pain, magnesium or muscle pain, magnesium supplements
1135 have helped an awful lot; they do nothing for me. So it's a
1136 real, you're on to a hiding into nothing, so I can understand
1137 the reluctance of a GP to try you on the latest... (Jessica:
1138 Oh yeah). The latest fad, for want of a better word. (Jessica:
1139 Absolutely).

1140

1141 I: I can understand both of your perspectives. I went to do a
1142 lit review last week and there were eight thousand things on
1143 one database. I found it quite confusing, and some
1144 information is so complicated, you think what does this
1145 mean? I can see the point that says, try it go for it, but also I
1146 can see that when does it end?

1147

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1148 **Jessica:** I don't believe in trying everything. (Steven: No
1149 no no). Please don't ever think that....

1150

1151 **Steven:** But the real problem is there are people out there,
1152 who- for want of a better word- exploit other people's
1153 weaknesses... (**Jessica:** Oh absolutely...) And the trouble
1154 with chronic conditions is that they are open to that kind of
1155 manipulation. And also with the best will in the world, your
1156 friends come up with things, have you tried this have you
1157 tried that? And you get to the point where you look at these
1158 things and you think to yourself, "well this must be a load of
1159 old bollocks". (**I:** Yes) Excuse me for saying that [laughs],
1160 because some of these, some of these therapies are clearly of
1161 a fringe nature. And the difficulty is getting a balance
1162 between having an open mind, a reasonable open mind, to
1163 say well actually this could work for medically sound
1164 reasons. This possibly could work compared with those
1165 treatments which you say well current levels of knowledge,
1166 this is a total waste of time.

1167

1168 **Tom:** If we're talking about treatments, I haven't mentioned
1169 up until now because I get sick of people's reactions. I've
1170 got a friend who is a doctor down south, who is also a
1171 homeopath, I mean he teaches homeopathy not just in this
1172 country but abroad, but he is a medical doctor. And I went to

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1173 see him, as I was thinking this just can't go on you know so
1174 and he has tried me on different remedies but one I took in
1175 November I really thought we'd cracked it because within a
1176 few weeks of taking it I felt like I used to feel. (I: Yes).
1177 And that lasted for about nearly two weeks ... and then it
1178 wore off and it's never been, I mean it's got him frustrated
1179 because.... (2) everything else he has given me. He has
1180 explained it to me- and I know about homeopathy – "I am
1181 trying to find a culture that fits the picture you are presenting
1182 me, and he said there are remedies that obviously are very,
1183 present a very different picture but you get, like colours in a
1184 rainbow so are side by side, and the subtlety of difference
1185 between them, it's sometimes very hard to find a remedy
1186 exact". So he said, "In a way it's trial and error". I said,
1187 "Fine I'd rather do it with a homeopathic remedy that can't
1188 hurt you than be experimenting with drugs". (I: Yeah sure)
1189 Erm, but it did make a, you know I really thought this
1190 November, we've done it! And I mean physically all my
1191 strength was back but- after two weeks I dropped down, but
1192 to be fair I'm better than I was last year, but I found the
1193 winter very hard. I got very sensitive to cold, my strength
1194 goes if I go out for a walk and it's cold. (I: Mmmmm).
1195
1196 **Jessica:** Yeah no one told me about seasonal variation.
1197 **(Steven:** Mmmmm).

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1198

1199 **Tom:** Yeah my doctor actually said in December, “You
1200 know if we have a hard winter you might find this is hard
1201 going”. And, you know most of us live in fairly warm houses
1202 and that these days, but if it’s cold outside it’s bizarre how it
1203 affects me. (I: Right)

1204

1205 **Julie:** Very much what going through with my GP is we are
1206 not trying to treat CFS at all. (Steven: Yes). She has
1207 admitted that she’s just not qualified, I don’t expect her to be
1208 she’s a GP she’s not a specialist. It’s about learning to
1209 manage the condition. (Tom: Yes). And what she treats are
1210 the symptoms. I’ve got, I ache, I hunch up, I work with a
1211 computer. All this creates bad posture; which creates bad
1212 headaches. She suggested that I get acupuncture for that. (I:
1213 Right). At my request finally for some painkillers, ‘cause I
1214 can’t always get out to the acupuncturist I like very easy. So
1215 just some painkillers that will help me make it through.
1216 Because it’s a very particular type of headache it’s like
1217 something’s been hammered from the back of my head to the
1218 front [she gesticulated the movement of pain with her hands].
1219 (I: Right). Mmm, she has suggested that I try yoga or the
1220 Alexander Technique, which is to get some gentle stretching
1221 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

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1247 where every now and again, you know, my boyfriend, he did
1248 it twice last week, turned up at my doorstep with a box full of
1249 stuff and he cooks, because he knows left to my own devices,
1250 I won't eat, or I might eat a dish of Cornflakes. (**Steven:**
1251 Right) Because my appetite has dropped and I don't have the
1252 energy to prepare a meal. (**Steven:** Yeah). So I can't be
1253 looking at adjusting my diet...
1254
1255 **Steven:** No, but well, that's interesting because you can
1256 argue that you do need, you are exactly in need of good
1257 dietary advice, in terms of the kinds of foods... (**Julie:**
1258 Well...) which are palatable to you...
1259
1260 **Julie:** But it's got to be easy to prepare...
1261
1262 **Steven:** Exactly, and also presumably one of the risks for a
1263 person in your particular situation, is that you may, you might
1264 be actually moving towards eating much more junk foods...
1265
1266 **Julie:** I do I live on cornflakes and frozen foods...
1267
1268 **Steven:** Foods that are low in nutrition...
1269
1270 **Tom:** That might exacerbate your condition....
1271

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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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1297 can't afford to buy lots of fresh food, I can't afford organic
1298 stuff, I'd love to because I'm pretty sure that chemicals don't
1299 help. But how do you do that?
1300
1301 **Steven:** But, but we're back to needing realistic advice
1302 aren't we. Because I think, because (2) somebody in your
1303 position, I mean an immediate response, I would so, well
1304 okay you haven't got a lot of money. So what you need to be
1305 doing is looking at cheap, you know, cheap nutrition. So for
1306 example, increasing the portion of fresh vegetables in your
1307 diet for example. Erm, eating more pulses, you know, all I'm
1308 saying, you is that it has to be tailored to the needs and the
1309 requirements of the individual...
1310
1311 **Julie:** It is a holistic thing isn't it. (**Steven:** That's right).
1312
1313 **Julie:** It needs a range of things. Now at the minute I'm
1314 being advised to try acupuncture try yoga, but I'm having to
1315 go out and find that for myself. (**Steven:** Yes).
1316
1317 **Jessica:** And again it comes back to the money thing. I
1318 know yoga works, I know acupuncture will help me. I know
1319 Chinese medicine will help me. Even though I was having
1320 continuous improvement with the Chinese Doctor, and he
1321 was going out of his way to, when I was saying that my

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1322 money is running out, this is really helping, sometimes you
1323 can really tell that it's the best treatment I've ever had. (I:
1324 Mmmm). And he was saying, well okay, instead of having
1325 this brand, we can treat, we can cut it down to this brand. I
1326 won't charge you for the acupuncture, just for the drug, you
1327 know the herbs. (Steven: Mmmm). Erm, so he was giving
1328 me consultations for almost half price. But that's all well and
1329 good, but (2) still I couldn't afford it for very long. (Steven:
1330 Sure). And it's gutting when you know something's
1331 working. I got no help to get this again. But then there is...
1332 (Steven: Yeah). And it's just like (3) I don't (2) I don't have
1333 the words for it, sorry.
1334
1335 Steven: Yeah, I mean it's horrible, but then you can also see
1336 it from the point of view of the service provider, you know,
1337 the health service, because the bottom line is that there is a
1338 limited amount of money to spend on healthcare. So
1339 therefore you have opportunity, therefore you have to, you
1340 have to spend that money on that which is proven. Or you
1341 believe is proven to have advantage. (Jessica: Yeah). And
1342 if something is unproven to have advantage in our society,
1343 like Chinese medicine, you can see that, that money isn't
1344 going to be there to do it. (Jessica: No but...) Which is
1345 heartbreaking for you as an individual because you know
1346 you're- you're the one who's caught up in that.

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1347

1348 **Jessica:** Absolutely but I mean, I mean the management

1349 thing we've kind of talked about, but the reason why I asked

1350 what advice you had been given by your doctor, was, I was

1351 given eat well rest well. Well that sounds like, when you're

1352 pregnant, put your feet up in front [laughs] of the telly, and

1353 try not to eat junk food. Yeah. I now know that if I manage

1354 things, you know, and the stricter I am the better it works.

1355 But I know I can't stick to that every time. You know, there

1356 will be times when people are like, "do you want to go down

1357 to the pub", and I'm like I have to be going to sleep by ten,

1358 sod it, I would like a social life as well. So every once in a

1359 while... (Tom: But...) I break it and I feel crap...

1360

1361 **Tom:** Sure, but that's quite healthy I think.

1362

1363 **Jessica:** Yeah. But nobody told me about this management

1364 early on. And I honestly believe that the earlier you try it, the

1365 more likely you are to have good improvement. You know if

1366 you need convalescence, you need it when you are recovering

1367 from the illness, not six months or a year later...

1368

1369 **I:** So bearing in mind...

1370

1371 **Jessica:** Does that make sense?

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1372

1373 **I:** Yes it does. I'm just curious that your symptoms started
1374 in 91', so over this time you've had lots of different advice. I
1375 mean, I know that both of you [directed at Julie and Tom]
1376 have said that your GPs have told you that they didn't know
1377 much about it but they would try and help.

1378

1379 **Tom:** Well I saw my own doctor and two doctors from
1380 [Company Name] that I was working with, and then a doctor
1381 from the Incapacity Benefit people, and they were all pretty
1382 supportive. They didn't disbelieve me, I mean they could
1383 spot most times that I was pretty exhausted...

1384

1385 **Jessica:** Someone from Incapacity was believing of you!
1386 [Demonstrated a shocked expression].

1387

1388 **Tom:** Yeah, he was fine. I mean I went there expecting an
1389 ordeal... (**Steven:** MM.). Because I knew, particularly with
1390 Government Legislation, but he asked me loads of questions,
1391 basically which was a repeat of the form I'd sent to in, and he
1392 did some tests on me, and I said, "What happens now?" And
1393 he said "Well I just submit this, all scored, and if you fall
1394 within the right scoring bracket you will get the benefit and
1395 you don't, then it's up to, you can either challenge it, you'll
1396 be..." (**Jessica:** What...) "Be seen by another doctor". But

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1397 it was about five days later, so my personal experience of that
1398 has been okay. But I know some people don't have that.
1399 (**Steven:** Yeah [sighs]). But in terms of very practical
1400 advice, I mean when you are seeing a doctor it is general,
1401 because they are general practitioners. They do advise you,
1402 just look at your diet, look at the way you live your life. You
1403 have to have personal responsibility and take on the detail of
1404 that... (**Jessica:** Yeah but...) I know when you're feeling
1405 bad, well for me it's been a case of (2) I hadn't wanted to do
1406 it, but when I'd gotten through the worse of that particular
1407 phase, I've then taken it up.

1408

1409 **Steven:** Yeah but then were back to this issue, that the
1410 bottom line, there is no, as far as I have been able to
1411 determine, there is no credible one source of information that
1412 you can get help here. And really, this is the kind of service
1413 that ought to be provided by...

1414

1415 **Tom:** Isn't this, isn't this the specialist service that we are
1416 going to see?

1417

1418 **Steven:** Well that's right! But you need general access to it.
1419 I mean what you've said is actually damning for the service
1420 that is being provided here in Leicester. The reason that I say
1421 this is because, I think that it is unacceptable for erm,

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1422 individuals who have been diagnosed with this condition not
1423 to be given access to information by a service which is
1424 purporting to help them. Now you were talking about, what
1425 nine months did you say that you've been so far on the
1426 waiting list? [Nods]...

1427

1428 **Julie:** The only letter I have had from them was to introduce
1429 you, they have never even acknowledged that they have
1430 received the referral. (Steven: Right...)

1431

1432 **Jessica:** I only got an acknowledgement because I phoned
1433 up to say excuse me...

1434

1435 **Julie:** My doctor's had a...

1436

1437 **Jessica:** How long is the waiting list.

1438

1439 **Julie:** My doctor's had an acknowledgement, which she's
1440 told me about. But I received that one letter...

1441

1442 **Steven:** So clearly there is an issue that the service is clearly
1443 clogged up in terms of the resources that it has got, in terms
1444 of the individuals it can see. But there is an issue, and okay,
1445 but there is an issue about what you do with people in the
1446 mean time. I can't understand why it's not feasible to

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1447 generate information packs, a good website presence, and
1448 basically to write to anybody who has been referred to say,
1449 you know, “You’re on the waiting list to see us, in the
1450 meantime that we have a helpline, we have this we have that,
1451 which will hopefully give you a bit of advice that will be
1452 useful while you...”

1453

1454 **Jessica:** Absolutely. The other thing that you ought to be
1455 told is an estimate of how long the waiting list is.

1456

1457 **Tom:** Yeah, you know, that’s true, as... (**Jessica:** Even
1458 if....)

1459

1460 **Tom:** You got no feedback whatsoever...

1461

1462 **Jessica:** Even if you are told, like, nine to twelve months.
1463 You’d be like “Oh bloody hell that’s a long time!”

1464

1465 **Julie:** But you’d know wouldn’t you...

1466

1467 **Jessica:** But the thing is that you wouldn’t be spending the
1468 first nine months going, “where’s my letter, where’s my
1469 letter?”

1470

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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

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1496 allowed me to work from home in the morning, which
1497 helps... (**Steven:** That's right). I work from home all day a
1498 lot, some of the time. And when I get bad, my doctor signs
1499 me off for two weeks with exhaustion. (**Jessica:** Yes). And
1500 I'm not quibbled about the amount of sick leave I'm taking.
1501 (**Jessica and Steven:** Right). However, I finished a major
1502 piece of work in the middle of last year. So my workload has
1503 been somewhat less than full since then. And now, they are
1504 starting to say "well your work load's not, and [Steven
1505 laughs] it's come to I've got to look at reducing my hours.
1506 (**Steven:** Erm). And I can't get, you know I've gone to my
1507 GP before and said "This is wrong and that's wrong, and I
1508 don't know how to manage this", and she's said, "What do
1509 you want me to do?" (2)
1510
1511 **I:** What is that like to hear?
1512
1513 **Julie:** Well it's devastating, but equally I'm realistic enough
1514 to know she is only human, she's a GP.
1515
1516 **I:** And she's been honest with you.
1517
1518 **Julie:** She is very honest, I have the utmost respect for her.
1519 Erm, but it's like, "You're my only port of call. If you can't

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1520 advise me, who do I talk to, 'cause I don't feel capable of
1521 making this decision on my own". (I: Right)
1522
1523 **Steven:** So we're back to, sorry, we're back to having a
1524 professional advisory. (Julie: Yeah). I mean I was, sort of
1525 thing was, well one of the things that struck me as being
1526 ludicrous was that I was looking at the whole issue of benefit
1527 because I'm not able to work at the moment. And the whole
1528 process of whether I could get, I mean the Incapacity Benefit
1529 was not particularly difficult for me to get, but the whole
1530 issue of whether I might be eligible for Disabled Living
1531 Allowance for example, there was nobody, the only place I
1532 could go to for advice was the Citizen's Advice Bureau. And
1533 I thought really this isn't really on.
1534
1535 **Julie:** And we don't even have that in [name of City]
1536 anymore.
1537
1538 **Jessica:** No. And also it varies, I mean at one point I hadn't
1539 heard of it for years. Then I heard about it I applied and I got
1540 erm, I was struggling to walk anywhere, but all I got was the
1541 ten pounds extra a week cause I couldn't cook a meal for
1542 myself. Then when that part finished, yeah, they said that I
1543 didn't need any help at all. And there is no balance, and the
1544 problem is that the forms don't apply to ME. Do you need

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1545 help? How many days a week? It's like, well some days, I
1546 need it lots; I have good weeks I have bad weeks. (Steven:
1547 Yeah [sighs]). And you're told you can't lie on the forms but
1548 if you phone up for help, they say, "Well if you average it out
1549 over the year how does it work out?" And the thing is, well I
1550 don't know, maybe I'm being silly, but there's this paranoid
1551 thing where you've said something on the forms. (Steven:
1552 Mmmm). And you know it's not a hundred per cent true, but
1553 then if you stretch it over the year it is, yeah, but then if
1554 somebody filmed you for a week, a good week, they'd go
1555 "You're lying your head off". (Steven: Yeah). So it's like,
1556 what am I supposed to do? (Steven: Yeah but...) And there
1557 is a big problem to me between, 'cause actually you need
1558 help from the benefits people and the doctors, and never the
1559 twain meet. They don't speak the same language, they don't
1560 communicate. And I'm at this point now that if I manage
1561 everything I can feel okay. Yeah. And I'm thinking I want
1562 to start working, but to do the job that I want to do, which is
1563 the only way I could work, sort of ten hours a week, which I
1564 can manage and pay my way, is to do a one day a week
1565 course for two years. But if I do that I might be proving
1566 myself fit to work. And there's this whole catch twenty-two.
1567 (I: Yeah yes). Where to keep myself well, you know, if you
1568 break the rules for keeping yourself well you'll end up for
1569 qualifying for higher levels on the DLA stuff. But if you

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1570 follow the rules, you don't even qualify for anything at all.

1571 And so, what kind of situation is that, it doesn't fit anywhere.

1572 There is no help for you to, to actually work steadily towards

1573 work. My GP would love to help me. He's actually sat there

1574 and said "Your plan is excellent, you are being very sensible,

1575 but I don't know how you are going to make it work with

1576 benefits".

1577

1578 **Tom:** This is, well that's all up for grabs anyway, isn't it!

1579 Cause perhaps after the election it's all going to change.

1580 (**Steven:** Yes).

1581

1582 **Jessica:** I mean my friend's got another problem, you know,

1583 she's just applied for Incapacity at the same time they are

1584 trying to cut down on people committing fraud... (**Tom:**

1585 Sure, yeah). And she's been told that she's got to keep

1586 working by her family, and I can see she's really not up to it.

1587 You know, she drags herself into work, is twice as ill the next

1588 couple of days, em...

1589

1590 **Steven:** You know, I think you are raising some very broad

1591 issues about the whole...

1592

1593 **Tom:** Yeah the politics of it

1594

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1595 **Steven:** The whole issue of the benefit system not being
1596 optimised to assist people in getting back to work. Cause as
1597 you rightly say. The other problem that relates to that is that
1598 there is a danger that it actually discourages people from
1599 getting better as well. (**Jessica:** Mmmm). Because it if you
1600 are financially penalised from trying to do a certain amount,
1601 then you are not going to try to do it. There's no incentive
1602 for people to try and work part-time if they know that their
1603 benefit is going to be taken away. And with a condition like
1604 this, where the condition that is so variable, you have got no
1605 safety net. Because if you go back to work and find a week
1606 later, a month later that you are back to square one, then you
1607 are into the whole rigmarole of having to claim benefit
1608 afresh, and so on and so forth.

1609

1610 **I:** I suppose, going back to your point earlier Jessica that
1611 may be compounded by the fear of doing something that may
1612 make you ill.

1613

1614 **Jessica:** And the thing is, it is a real physical illness with
1615 psychological consequences, and it's one thing I was going to
1616 try and bring it back to anyway. I think the service needs to
1617 be not just about learning to manage and stuff, but also
1618 there's a psychological component that goes with being ill for
1619 a long time. (**I:** Yes). It gets you down. It's people not

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1620 believing you, and I would love to be in a situation where
1621 once every so often, there is somewhere I could go, and I can
1622 just go “Blurrrrr” [gestures verbally pouring out]. (Tom:
1623 Yeah). Here’s some of my madness. Here’s my frustration,
1624 here’s my grief, just have it [laughs].

1625

1626 **Tom:** Yeah yeah, that kind of support would be a great
1627 resource.

1628

1629 **Jessica:** And it’s also something, I mean, when I was living
1630 in [place name] there’s a charity there called [name of
1631 charity], and they provide a counselling for people with ME,
1632 and the counsellors know about ME. So instead of having a
1633 complete non-interference thing going, they’ll actually say to
1634 you, “I’m really glad you’re feeling better but do you think
1635 you’re being realistic about the amount you want to do?”
1636 And that is a really hard thing to hear, but you need
1637 somebody to say it. Because every time I feel better, I
1638 always want to do too much, it’s just your natural drive is to
1639 do what you can.

1640

1641 **Steven:** Can I ask a question about, I mean one of the areas I
1642 wanted to just ask about was, erm, the whole issue of self
1643 help groups and experiences of self help groups. (I: Yes).
1644 Because it struck me that one of the areas where assistance

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1645 could be provided is in actually providing assistance for, you
1646 know, such groups to be put together, and to also help them
1647 in their activities. I mean I'm, I'm loosely involved with a
1648 group, a [name of city] support group called [name of support
1649 group]. And that was really by chance, by me sort of looking
1650 on the internet and trying to find, well you know, thinking
1651 should I get involved with this sort of group or not. (I:
1652 Right). And it struck me that these are people who are trying
1653 their best to help other people, and they're struggling
1654 themselves, and it would have been incredibly easy for, you
1655 know, a service to provide some administrative support to set
1656 up a website to help people get in touch with other people.
1657 But that side of it just doesn't seem to be part of the service
1658 delivery mechanism.

1659

1660 **Jessica:** In some ways I think that is a really good idea but in
1661 other ways I have to say, my experience with [name of
1662 charity] was incredibly positive. My experience with some
1663 other groups has been, erm, "Oh yes, I'm really ill" [makes
1664 muttering noise of someone talking]". And it's all about this
1665 person, and then they're telling me they found out about this
1666 research project, and this one and this one. And you come
1667 round to the point of, well how did you find out about that,
1668 and suddenly they clam up, because there are limited places
1669 on any research project and they don't want to spoil their

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1670 chances of getting onto it by telling you. And I just felt like I
1671 was just getting this, "I'm iller than you". And I don't want
1672 any of that crap. I know that sometimes I've been much iller
1673 than I am and I've been much better than I am. (I: Mmmm).
1674 And I don't want to get into a "I'm iller than you are, I've
1675 had it for two months more than you". I don't give a toss!

1676

1677 **I:** Well I think that that can happen...

1678

1679 **Jessica:** but....

1680

1681 **I:** That is really up to the group members to manage that
1682 dynamic.

1683

1684 **Jessica:** There are people that haven't.... (Tom: Yeah).

1685 There are other people that haven't been ill for such a long
1686 time that have been much iller than me. Or they have had
1687 more supportive or less supportive families. Your experience
1688 isn't just to do with how long or how bad.

1689

1690 **Steven:** Yeah. The good advice that I've received in terms
1691 of dealing with this condition has been either been a
1692 combination of either me looking on, you know, trying to
1693 gather information and read books on the internet. But also, I
1694 have to say, from talking to other people, who have said

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1695 “Well look, I have had this problem and I found this helps
1696 me, have you tried this, have you tried that”. I think you’re
1697 right, there is a danger, I mean, it’s a balancing act because
1698 there is a danger as well that you, I mean nobody wants to
1699 spend all of their time talking to people who are sick. Let’s
1700 be honest, I have no desire to spend all my life talking to
1701 other people with ME. (I: Yes).

1702

1703 **Steven:** But I do think there is a place, if it is carefully
1704 managed, for advice to be.... (Tom: Yeah). And also
1705 support as well ‘cause we know there aren’t resources to
1706 provide the support you actually need. I go to my GP maybe
1707 once a month. Fifteen minutes is maximum time that, that,
1708 for an appointment with that person. That is, for somebody,
1709 you know I can’t do a brain dump in fifteen minutes with the
1710 problems that I am having [all members laugh]. (Tom:
1711 Certainly). You know, he only wants to hear one fart
1712 [laughter continues]. He says, “That’s it, I’ve had enough! I
1713 can’t help you with it all”. And you need, you need...

1714

1715 **I:** Do you think there is something about the professional
1716 feeling that they cannot help you, so that creates a feeling of
1717 uselessness in them, that may be pushed back onto you?

1718

1719 **Tom and Jessica:** Yes...

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1720

1721 **Steven:** Absolutely...

1722

1723 **Julie:** Yes it frays their expectations...

1724

1725 **Steven:** We're back to chronic conditions being incredibly

1726 difficult to treat. And your doctor wants to have an acute

1727 condition because it's easy to treat an acute condition.

1728 **(Jessica:** Mmm Mmmm). You know, this person has got X

1729 and we'll give them Y, and they will get better or we'll try

1730 another treatment. Whereas with something like ME, I mean

1731 you're into a hike into nothing, and it's depressing for the

1732 doctor. You know, you know there's jokes about what

1733 appears in people's medical records, you know like "God

1734 only knows" you know, things like that. Because there is a

1735 hardcore of patients who keep coming back with chronic

1736 conditions which the GPs can't do anything about. **(I:** Sure).

1737 And unfortunately we fit into that category as well.

1738

1739 **Jessica:** I've got a slight problem with hearing resources all

1740 the time.

1741

1742 **Tom:** But it's true though isn't it!

1743

1744 **Jessica:** It's nothing personal.

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1745

1746 **Tom:** No, it's a fact of life.

1747

1748 **Jessica:** It is, but no, my problem is that ME is not, I

1749 suppose I keep saying, sexy illness, you know, it's not very

1750 exciting, it's not media-worthy particularly or anything. But

1751 there are a hell of a lot of people out there with it, and the

1752 resources provided for us do not in anyway connect with the

1753 amount of people with ME, you know. There are, I think,

1754 four or five centres that deal with ME, and by that what we're

1755 talking about is clinics like the one in [name of city] yeah, in

1756 the country. (**Tom:** Mmmm). Yeah. Now I know as many

1757 people, [one tape goes stops loudly], one of them is recording

1758 isn't it? (**I:** Yes). I know as many people with ME, probably

1759 more than I know who have had cancer. Yeah... [Julie

1760 sighs]. (**Steven:** Yeaaaaah).

1761

1762 **Jessica:** Now I know cancer kills you...

1763

1764 **Julie:** Yes this is a point. There are people dying for the lack

1765 of intensive care beds. (**Jessica:** Yes)

1766

1767 **Julie:** And that's got to be more of an immediate priority...

1768

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1769 **Steven:** Yes, and also, also it is impossible for, as an
1770 individual to see a broader picture, because our own
1771 experiences draws us to people with similar, we become, our
1772 experience is based on the contacts we have and the circles
1773 we move in. So, so, it needs to be based on acuteness and
1774 also on demographics, in terms of most common diseases,
1775 and debilitating diseases and so on. But having said that, I
1776 think you are absolutely right, not enough has been done
1777 about this condition, because there is still the attitude, and
1778 I'm fortunate because I've not experienced it directly, but I'm
1779 told by a variety of people that have had this condition for a
1780 longer period of time than me, that there is still that attitude
1781 that, you know, this is not a real condition, this is, you know,
1782 a psychological problem... (**Jessica:** Yeah). You know, all
1783 we need to do is, is give the person some cognitive
1784 behavioural therapy, give them some graded exercise, and the
1785 problem is going to go away.

1786

1787 **Jessica:** Mmmm. I would like to actually have a list, I mean,
1788 every county to have a list of doctors who believe in ME.
1789 Because when I moved from [name of city] to [name of city]
1790 I phoned round all my local surgeries and I actually had a
1791 situation where, I phoned up the receptionist to say, "How
1792 does your doctor feel about this?" And one of the doctors
1793 grabbed the phone off his receptionist and said, "No, no no

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1794 ME is not real, what you have is depression and I can treat
1795 that and I can make you better". My response was "Thank
1796 you but no thank you". [General laughter from participants].
1797 (Steven: Next!). I'm really not interested, and he tried to
1798 keep me talking. But the thing is right, have you tried finding
1799 a doctor who believes you, No – I mean, it's really difficult!
1800 And because of things like the Data Protection Act people
1801 keep saying, "Well we can't keep lists like this". So you end
1802 up finding people with ME and going "So what doctors have
1803 you heard good reports about?" (Tom: Absolutely). You
1804 have to go by word of mouth and then it's really down to
1805 potluck. And with me you know, I'm now at the second
1806 surgery in [name of city] after having done my phone round
1807 and it's marvellous, it's one of the best doctor's surgeries I
1808 have ever been to and the thing is I don't now want to move.
1809 (I: Right). You know it's insane to base where you live by
1810 the doctor you've got. But the reality is that if you have a
1811 chronic condition, your GP is actually a very important factor
1812 in your life.
1813
1814 I: Can I just draw your attention to the time. How is
1815 everyone? [Laughter]. I have found this is very interesting,
1816 and I am thankful to gain this insight. Is there anything that
1817 anyone would like to say briefly, if you feel like you have not
1818 had the opportunity to say it so far?

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1819

1820 **Jessica:** Yes I would like to say that when you go into
1821 hospital, you are usually placed in wards with old people that
1822 moan or outright chat when you are trying to rest. This is not
1823 a good place to be when you have this condition. You come
1824 out feeling worse!

1825

1826 **Julie:** Yes but that is probably most people's experience
1827 with a range of different conditions.

1828

1829 **I:** How have you found the discussion today?

1830

1831 **Tom:** Yeah, useful

1832

1833 **Jessica:** I could just talk and talk about it

1834

1835 **Steven:** Yeah

1836

1837 **Julie:** It's been okay, I wouldn't like to do it too often. But
1838 if there is anything you need to clarify I don't mind you
1839 contacting me.

1840

1841 **Tom:** Yes

1842

1843 **Steven:** Yes of course

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1844

1845 **I:** Well thank you for participating in the group.

1846

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.

1847

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Venue: Activity Room at the Cedars Centre, 5 Participants

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

6 (Group agreement).

7 Basically what is going to happen with the results is probably
8 more towards the middle or end of this year I will be handing
9 my research in. I will be looking to publish the results-
10 hopefully in a journal that the medical professionals may
11 access. I will also produce a report to go to the Chronic
12 Fatigue Service and a report will be sent to you. Is that okay?

13 (Group agreement).

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

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

22 So ground rules – really if I may propose the first one is that
23 basically what we discuss today stays in the room today.

24 [Participants show agreement] Has anyone else got any
25 suggestions that they would like to make, like what would

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26 make them feel more comfortable? (4) No, right okay. So it
27 is ten to three now. How do you want to do this? Shall we
28 talk for half an hour and then have a five-minute break and
29 then go for another half an hour?

30

31 **Pat:** Don't mind!

32

33 **Fiona:** It's nice to have a middle break

34 [Others indicate no preference].

35

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

38

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

41

42 **I:** Is four pushing it or is that okay?

43

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

45

46 **I:** Okay well thanks for saying that. [Turns to assistant
47 researcher] and can you keep an eye on the time? (**II:** Yes).
48 Also there is another form that I wanted to give you, basically
49 what this is - a lot of it I already know from talking to you on
50 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 **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 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 going mad, I honestly did. And
73 when I read those books I thought well that could be me –
74 what I was reading – that could be me! And that made me
75 feel better to start off with. And erm, (2) it's not been easy.

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

88

89 I: So she's managed to get back to work.

90

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

94

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

97

98 **Pat:** Oh yeah, yes. If I hadn't- I mean some people don't
99 believe in it. And I know a lot people who don't believe in it
100 and there are a lot of doctors don't believe in it. And if I'd

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101 have gone to somebody like that, well I don't think I'd – well
102 I most probably would done away with myself before now
103 [laughs]
104
105 **I:** Right- you said, you thought you were going mad?
106
107 **Pat:** Yeah I did – I did.
108
109 **I:** And so you had a GP that was sensitive to ME...
110
111 **Julie:** Yes, Yeah, Yeah, Yes.
112
113 **I:** And knew that you had CFS. Okay what has other
114 people's experiences been like?
115
116 **Rachael:** Everyone's looking at me so [laughter]. I've had
117 chronic fatigue syndrome for nine and half years. Erm (2)
118 and my experience with the health service has not been that
119 good. Erm to begin with it wasn't that good – nobody knew
120 what was wrong and they just put it down to the fact that I
121 didn't want to go to school. XXX. Erm and you know
122 because I had ME that's what started it off. Ehm, I know
123 some of it is psychological I know that now. (**I:** Right). And
124 I know that a lot of it isn't (1). And a lot of doctors try to fob
125 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

150 terminated my contract – it's like being sacked and it's not
151 very nice.

152

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

158

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

161

162 **Rachael:** No this is a different doctor – we changed because
163 we moved you see. So even though the doctor before was
164 fantastic, really, really good and helped me get back in to (1).
165 Cause I was, I was, I've been in I had to stay in bed for like
166 two years. Well I felt anyway- because I felt too ill. And she
167 got me back into the open – she used to come to my house
168 and used to walk me to the front gate, once a week and then
169 down the road and then back. (**I:** Right). Eventually after so
170 long, after two years I ended up doing voluntary work two
171 days a week. And it's just escalated from there. But now
172 I've moved because it is quite traumatic moving and
173 everything it can be quite stressful. The doctor that I'm
174 seeing now- because you have to change doctors she is not

175 that understanding. (I: Right). Even though I am seeing
176 [name of psychologist] I still have to go to her with certain
177 problems and she is not that understanding. Until I went in
178 and said, "Look I am trying to say to you this is how it affects
179 my life". I'm saying, "I'd rather have no legs than feel this
180 bad in any morning". Some days I feel okay! Some days I
181 don't.

182

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

187

188 Rachael: I think what I'm trying to say by that is I got into a
189 routine. Okay I, I got on a bus once and I had a really bad
190 spell on the bus. I had this issue about people looking at me
191 – but anyway that's a different thing – but anyway something
192 bad happened on the bus, and then I had this psychological
193 thing that every time I got on the bus something bad was
194 going to happen to me. Then it got escalated to like someone
195 would end up killing me on the bus, [laughs] but at the time it
196 feels real. When I look back I think, "Ooh what are you
197 doing you're such an idiot". But at the time it's so real and
198 its like everyone wants to hurt me why? But then when I
199 think back on it I think, "No". So I try to break that by going

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200 on the bus even though I hated it – I got on the bus. (I: Yes).

201 And I'd cry- literally want to cry – but I'd get on it because if

202 I knew if didn't get on the bus I'd just end up [laughs] not

203 going anywhere and I wasn't going to let that happen. (I:

204 Right).

205

206 **Fiona:** Very well done there!

207

208 **Rachael:** Thank you, thanks.

209

210 **Pat:** I couldn't even leave the house for a little – for ages! I

211 couldn't face people who knew me, because I looked such a

212 mess as well as feeling such a mess.

213

214 **I:** Right so there was something about feeling a bit

215 embarrassed or a bit ashamed about...

216

217 **Fiona:** Because you look fairly normal. Erm, a lot of people,

218 you know you try and explain that you are disabled and you

219 can only walk a few feet or whatever- and people are like,

220 "yeah right, sod off, stop trying to draw attention to

221 yourself". And fortunately I've had many years and found

222 myself surrounded by friends, who are very understanding

223 and realise and are interested in what's wrong with me but

224 not to a sick degree. (**Rachael:** Mmm yeah). But you do get

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225 a lot of, “Oh come on pull your socks up”, even from doctors.
226 It took me (2) it took me three & half years to get a diagnosis
227 by which time I had been – I’d lost my job – I had to drop out
228 of college – I’d therefore lost my flat – I’d spent about six
229 months in squats and sleeping rough – I finally got a flat
230 completely collapsed and been bed-bound for about a year!
231 Which was nice! And that was- I’ve been ill for eleven years
232 so that’s a hell of a long time ago.

233

234 **Rachael:** You’ve done well as well yeah to get yourself
235 back...

236

237 **Pat:** What I get now though – what does me mostly now is
238 like disbelief as you said from people. I mean I stopped
239 going out – I got a local across the road from me and I
240 couldn’t face going in. And I got to go in, you know, with
241 the help – I did go in with [name of therapist] you know
242 talking to me. Even now people are say to me, “Oh you’re
243 lazy you are. What time did you get up today? Why don’t
244 you go to work?” This has really been getting me down
245 again just lately. (I: Right). It really, really has – it’s what
246 people think about me. I mean I’ve worked for thirty-three
247 years, and you know it’s like, “Oh it’s alright for some
248 they’ve not got to get up for work”. And it just gets to you
249 sometimes, you know, just leave me alone, but they don’t

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250 they keep on at me and on at me and it's though it's their
251 problem I'm not at work, do you understand me, and then I, it
252 upsets me.

253

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

256

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

259

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

262

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

268

269 **I:** Right by saying that you are beginning to look normal
270 again do you think there is a link between people saying to
271 you, you are lazy why aren't you at work and all this because
272 you look normal? **(Pat: Yes, yes).** Right.

273

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274 **Fiona:** I suppose because I've had the benefit of being ill so
275 much longer, I've got completely used to handling it. I don't
276 always handle it well but ...

277

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

281

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

283

284 **Julie:** Yes – not family. It was family as well – it was the in-
285 laws at first. (I: Right). Because my in-laws I think they
286 thought I was putting on my husband. But how I got over it
287 the past two weeks – 'cause I said it was really getting me
288 down and I saw [name of therapist] last week and she had a
289 good talk to me a couple of weeks back and I thought, "No,
290 I've been to work and I've done my bit. I've paid for my
291 house, I've paid my house off – my mortgage – I've done my
292 bit. And this is how I've got to keep looking at things to
293 make me feel as good as what they are – if you understand
294 me. [Different participants acknowledge what Pat said]. If
295 not I start going down again, and it gets me down. And
296 something else will bring me down if I'm not careful.

297

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298 **II:** I'm sorry; I was just wondering what your experiences
299 were at the health service as well? [Directed at the two
300 participants who had not spoken].

301

302 **Fiona:** [Chuckles]. The quiet people.

303

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

316

317 **II:** Were there, sort of - obviously I mean that's a lot about
318 you doing that, but I wondered if there was certain people I
319 suppose, well professionally that you saw professionally but
320 also in your personal life that kind of helped that or hindered
321 it?

322

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323 **Collin:** Well before I was first diagnosed – it took two years
324 to find out what was wrong with us – I was back & forth to
325 the doctor's, "Oh not you again", and that was their opinion.
326 "Not you again".
327
328 **Julie:** It's awful ain't it?
329
330 **Collin:** You know, until (1) a new doctor came to the
331 practice she noticed all the different ailments, and she sent
332 me to the err, place and I got assessed and all that. Once I got
333 it, they said you've got this syndrome sort of thing and that
334 was it. And since then it has been a gradual progress, getting
335 better, better and better - I wouldn't say I'm 100% but I will
336 get there – it's just gonna take time but until I got diagnosed
337 it was horrendous. You know (2) you would walk in and the
338 receptionist she would tut, you know you could hear her tut
339 before I'd even walked through the door. They all thought I
340 was just putting it on. As you say you know you think at the
341 time as Rachael was saying, you want to chop your arms off
342 or something like that. I didn't want to got to work, but I had
343 to go to work to pay our mortgage. And when you're at work
344 you're not producing enough err stuff, and they're on your
345 back. So it's all a case of everybody (XXX) just piling on
346 top of you and then you are trying to swim with a boulder on

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347 you and it's hard. Hopefully I'm starting to get better but it's
348 gonna take time.

349

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

351

352 **Collin:** Since I've been on the programme yeah. He does

353 talk to us and...

354

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

356

357 **Collin:** Oh it was horrendous! (**Pat:** Yeah). I didn't realise

358 what I had, and that was a problem- in- you feel so ill

359 sometimes as you say you don't want to get out of bed- but I

360 had to get over it because I owned a house so I got to pay for

361 the mortgage. Even though I was (2) some days I just used to

362 stand there and just do the work, talk to nobody. My mate

363 said, "How are ya. He's got it on again (XXX)". I wasn't I

364 just ... I didn't want everybody just getting on my back. (2)

365 And then when they come to see you (2) for reviews and

366 everything (2) it's "Oh you're not talking to people you know

367 you upset a lot of people because you're not talking to them".

368 You know I wouldn't stop them coming to talk to me (XXX).

369 (**Pat:** No). And that's how I got it across. Eventually it's

370 starting to get a little bit better – as I say it takes time.

371

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372 **Fiona:** It's amazing the people who drop you like a hot brick
373 once they realise you're ill long-term isn't it?

374

375 **Collin:** Oh yes, the friends I had – see I had just moved to the
376 area. (1) I had a small group of friends which I thought were
377 good friends but soon as that happened bump! That was it.

378

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

382

383 **Collin:** Well as I say the doctors used to say, "Oh well
384 what's wrong now". You know, he used to give me
385 prescription after prescription- none that helped. Until I
386 found, you know, I had certain problems and once I got the
387 booklet and read the booklet it just hits you – don't you think.
388 **(Pat: Yes, yeah yeah).** It's me.

389

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

391

392 **Collin:** Once I read the book...

393

394 **Pat:** Yes I was just saying yeah.

395

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396 **Collin:** I'd wasted 3 years sitting on my- well not sitting arse
397 (2) but I didn't know what was wrong with us. But once you
398 get that information you think well. It just ...

399

400 **Pat:** It's like talking about you ain't it? It is really like
401 talking about you isn't it!

402

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

405

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

407

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

410

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

417

418 **Rose:** I think on a good day it makes you angry like Fiona
419 said, on a good day it makes you angry on a bad day it just
420 makes you want to go to bed and stay there. So if you can

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421 get angry then you are having a good day cause you've got
422 the energy to get angry [laughter].

423

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

425 [Agreement by all].

426

427 **Rose:** You just want to cry really.

428

429 **Julie:** How did you get help?

430

431 **Rose:** Erm, my experience is similar to Rachael's really

432 because years and years of not getting any help from doctors

433 whatsoever and basically them saying either, "It's all in your

434 mind or it's your age – is what I often got".

435

436 **Rachael:** Yes it's your age [laughs].

437

438 **Rose:** It didn't matter what age I was it was definitely my age

439 that was doing it [laughter]. So it wasn't much help but I

440 work in alternative health so I have a lot of support in that

441 area and actually have worked with many people with

442 chronic fatigue syndrome myself and had helped them.

443 (**Julie:** Oh right). So basically I turned myself into my own

444 patient if you see what I mean, and had to work with myself

445 for many, many years and it is only in the last couple of years

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446 since I had a new doctor- who is just wonderful, he is great,

447 so...

448

449 **Pat:** You two had had it quite a while, do you think I mean

450 I've had it nearly two years do you think they are getting

451 better then now in understanding it?

452

453 **Rose:** I still think it depends who your doctor is. I don't

454 think it is necessarily getting better although I am amazed

455 'cause I didn't know about this service. Erm, and I would

456 have thought that I would have known about service through

457 many of my own patients and not one of them had sort of said

458 to me that they had any help from their doctor. I have

459 worked with maybe ten over the years, ten different people

460 and not one had.

461

462 **I:** So this is not very well publicised.

463

464 **Rose:** It doesn't seem to be to me- but then I'm in [name of

465 city] so this is a long way from me. (I: Right). It's a long

466 way for me to come actually to get some help. I think you

467 know its sort of allowing an hour-, which is not really good

468 enough for the NHS, is it! [Laughs]...

469

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470 **Rachael:** My psychologist comes to me – sorry (**Rose:** It's
471 all right). Just to say my psychologist comes to me 'cause
472 sometimes...
473
474 **Pat:** Oh that's good isn't it.
475
476 **Rachael:** Yes. He'll say do you want me to come to you or
477 do you feel well enough to come to me? (**Rose:** Well that's
478 great). And we'll compromise- even though I've not seen
479 him for a couple of months because we've been moving and
480 so on but...
481
482 **Rose:** I think that if I hadn't have done everything that I have
483 known to do over the years...
484
485 **Rachael:** You've taught yourself haven't you? (**Pat:** Yeah).
486
487 **Rose:** I would have been disabled years and years ago –
488 really I would have, you know. And I've sort of pushed and
489 pushed and pushed and tried to get through it, but then in the
490 past 3 years, through erm things that have happened that I
491 haven't been able to control, it has just got so I couldn't do it
492 any longer. And then actually that was the time when I got
493 this new doctor who sort of said, "Well how about we look at

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494 this in a different light. Which is great – it's really good!"

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

496

497 **Fiona:** I think there are more and more getting switched on

498 to it but it's still a lottery. I've got a doctor who is very

499 understanding about the fact I have got ME but that's it.

500 Whatever I go in with now it's, "Oh it's the ME". I could

501 hop in with a severed leg over my shoulder and it's, "Oh it's

502 the ME". [Laughter] (**Rose:** Yes, absolutely. [Laughs]). I

503 feel. I feel like I need access to more services I know are

504 there, [name of therapist] can't send me and she's - the big

505 thing [name of therapist] done for me is just been supportive,

506 we are doing a bit of cognitive behaviour therapy and she's

507 there when the disability living allowance forms need

508 helping- because the physical therapy we tried made me a lot

509 worse. Erm, but I'm- you know the GP's just, "Oh it's the

510 ME go home". And [name of therapist] can't send you on

511 anywhere or prescribe anything erm. (**I:** Yes). The main

512 thing I'm having problems with at the moment is I'm in a hell

513 of a lot of pain- and I'm not sleeping because of it, and I just

514 can't get anything – I can't afford alternative therapies – I

515 can't get to the pain management place that I know there is at

516 the hospital. There is nothing – I daren't even take co-

517 codamol because I will get addicted to them because I'm

518 eating Paracetamol like Smarties and they would just take

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519 about the edge of things and ... (I: Right). I feel like my GP
520 is like a bouncer & I can't go in because I'm wearing trainers.
521 I can't get to the things. There is so many little threads that I
522 need to pull together and if I can pull these little threads
523 together I'll be in the optimum place to start going up hill
524 again. Because I know I can get to the stage where I can
525 work full time I've been there and I relapsed. I got a chest
526 infection and relapsed, and because I've been kind of been
527 thrown on the scrap-heap at that point and not helped it has
528 got to the stage where it's you know every other day I can
529 perhaps get out of bed. And I can barely walk and I refuse to
530 use my wheelchair because it's bloody uncomfortable and I
531 don't want my legs to waste away – I don't know what
532 happens to legs if you don't use them – I want to keep on at
533 them but. (2) Yeah I think with any centres it would be lovely
534 to have a way that all these things could be in one place and
535 maybe even a little more local. (I: Okay). Cause it is a hell
536 of a long way for me as well – it's not as far as you but I've
537 got to go through sort of south [name of city] countryside
538 right up to the [name of hospital] on the other side of the city.
539 And it takes it out of me by the time I see [name of therapist]
540 I'm insensible. [Laughter] I just gibber at her [laughs]. (Pat:
541 She's lovely though). She's fab.
542
543 **Pat:** She's lovely she really is.

544

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

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

559

560 Pat: Yes. Well actually I suffer with my back and
561 everything and it's like you say it's expensive to keep having
562 these things done. And it's - like I pay £30 a time to have me
563 back all done because, like you say your body aches and that-
564 and she's been lovely as well (name of therapist) and err,
565 she's an occupational therapist, and I've bought some in-
566 soles from her they did cost me £50 but they have got little
567 magnets in and they do – you might think it's all in the head
568 but they do help me – they give me – they magnet parts of

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569 your feet and they do help my body. But as you say things
570 are so expensive you know – you do try to help yourself –
571 anything if you can.

572

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

575

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

577

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

583

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

587

588 **Fiona:** Like acupressure almost.

589

590 **Pat:** And they do – yeah – honest they do help. I find them
591 really helpful.

592

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593 **Fiona:** I mean I have spent like 600 quid on a mobility
594 scooter because I knew it would help. 'Cause I knew it
595 would help I could throw that money at it. Erm, I got some
596 disability living allowance back-pay and it's a godsend
597 'cause it's the only way I ever get out of the house and it's
598 only perhaps once a fortnight I manage to get out. But you
599 know could pootle round the block and it's better than
600 nothing. (I: Mmm)

601

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

603

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

609

610 **I:** I mean there does seem to be a lot of uncertainty about
611 ME and knowing how long you are going to have it for and
612 how to cope with it. I just guess there is so many things like
613 this works and that works et cetera and it's an individual
614 thing isn't it? Some things work for some people, some
615 wouldn't work for somebody else but ...

616

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617 **Pat:** Well we don't know what causes it – people say it's a
618 virus, somebody else like Rachael say it is psychological, I
619 mean you get all these different things off people as well
620 (agreement by all). I still don't know what causes it now?

621

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

623

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

626

627 **Fiona:** I haven't read that

628

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

633

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

637

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

640

641 **Pat:** Did you have you?

642

643 **Rose:** Yeah I did I fell off the ladder. (**Pat:** Oh dear).

644

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

652

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

655

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

660

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

663

664 **Rachael:** I make a big issue of everything though; I don't let
665 it just go. They say, "No you have to go to them", and then
666 I'll take it a step further but I say, "Well, you're not disabled

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667 are you? So it's alright for you to say that to me". That's the
668 kind of thing I'd do.

669

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

671

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

675

676 **I:** But I guess you have to be fairly assertive

677

678 **Rachael:** You have to be firm, if you're to get anywhere you
679 have to be firm- because you don't get nowhere. People
680 don't listen to you unless you tell them – "this is what I am".

681 It's like when I used to work – you can do so many hours

682 working with the disability- I basically told the boss well

683 alright – yeah you can have the job but what I'm saying to

684 you some days I won't be able to come in – do you

685 understand that... (**I:** erm). Because that is who I am – some

686 days I won't be able to come in because of my disability – I

687 know now they can't discriminate against you [agreement by

688 all] – but it is still quite hard to explain to your boss – I can't

689 carry that heavy box from there to there. I can't carry those

690 boxes.

691

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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

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717 relationship with your therapist. I know Pat you said some
718 things about it – you all have in different ways. What do you
719 think, what for you are the really positive factors out of your
720 relationship with your therapist – if there are any?

721

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

726

727 **I:** So that's somebody in your corner?

728

729 **Fiona:** Yes absolutely! And I'll say "Ooo, I felt a bit rough
730 because." and she'll sort of finish the sentence, and I think
731 "Oh my God".

732

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

735

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

738

739 **Pat:** Well believing in you I suppose and really trying to
740 help you. (Fiona: Yes). The best she can.

741

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742 **Fiona:** It's that understanding, constructive understanding not
743 just, "Oh dear poor thing ahhh" – constructive understanding.

744

745 **I:** Yes okay. What have you made of it [looking at Collin]–
746 sorry to put you on the spot Collin, [All laugh]. In terms of –
747 I mean is there anything useful that you have found from

748

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

758

759 **I:** And setting realistic goals

760

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

767

768 **Rachael:** It's the weather

769

770 **I:** Yes there is something about consistency that in a way

771 you have got someone to see that's providing some

772 consistency in reviewing how you progress?

773

774 **Collin:** Sort of, well you know he's in, as you say he's in

775 your corner, sort of thing. I get a chance to talk things

776 through with him and he will criticise it and say, "have you

777 been on the run", sort of thing but I haven't really run for

778 about six years now or so. (I: Right). So I've gradually built

779 my running back up.

780

781 **I:** Right okay, so he is using things that you're interested in as

782 well, 'cause I was just thinking I suppose for somebody else

783 if running wasn't your thing – I mean I would be horrified if

784 someone said to me to run. [Rose laughs]

785

786 **Pat:** Oh no they tell you to try to find an interest. Like I

787 walk dogs now. (I: Right). She asked me, "What do you like

788 doing, there must be something", and I love animals – I just

789 love animals. She said right find yourself something to do

790 with animals- and I do it voluntary walking dogs. (I: Okay).

791 I've had tapes off her – relaxation tapes as well – you know

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792 she does – if you’ve got anything and you ask her the next
793 time and she’ll try and sort it out for you.

794

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

796

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

801

802 **Rachael:** [name of therapist] he just really gives me sheets to
803 read. I don’t think he is really up on what’s going on. He’s
804 good don’t get me wrong and he has helped me a bit but he is
805 not (3) he just gives me sheets to read basically and fill out a
806 diary and stuff like that. I don’t think any of it helps! But he
807 does give me advice but not any that’s really going to change
808 me that much. I have always been self-help, that’s what I’ve
809 found. (I: Right okay). Cause (3) that’s the only way that
810 I’ve ever found anything useful in reading books- but he has
811 been a bit good in some ways. I think if you want help you
812 have to kind of find it out yourself. (Pat: Yes you do). It’s
813 like college- I had to go and tell them I wanted to do this
814 course, I mean I’d love to go to university- in reality I don’t
815 think I will be going. One I can’t afford it because I’m on
816 disability and two I don’t think they would cater for my

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817 needs. (I: Right). But I would love to go – but luckily at
818 college they are quite good and understanding. But I have
819 had to go forward and tell them can I have extra days to hand
820 in assignments, can I have a support worker! And I have had
821 to do it all myself.

822

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

829

830 **Rachael:** It's because you can't see it!

831

832 **I:** I think that actually taking what you have just said very
833 concretely there is something about not seeing isn't there –
834 for example, your arm is not in plaster – perhaps other people
835 struggle to understand. I was interested in this thing about
836 Fiona I think you were saying you having CBT, and I am
837 aware that some of the treatments you are having are
838 different to that. I guess yours would be along the lines of
839 cognitive approach as well [directed at Pat]. I am interested
840 as well Rachael, I guess what [name of therapist] was giving
841 you would be part of particular type of approach. (**Rachael:**

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842 yes). Which doesn't sound like you are finding that
843 helpful... (**Rachael:** It's not) From what you've said.
844
845 **Rachael:** Not really. I've just got kind of to the end of being
846 bothered with it now. 'Cause everything is – the thing is –
847 you know I've been to doctors I've had all these tests- none
848 of that ever helped – different ways of thinking – yes some of
849 that has worked but some of it doesn't.
850
851 **Fiona:** It doesn't actually help the ME I've found. (**Rachael:**
852 Yeah). It helps the misery that happens because of ME or it
853 can do, or it can help you think positively. But the actual ME
854 (2)– you know I was absolutely fine mentally before this –
855 there was nothing wrong with me – you know I was a figure
856 skater – it was brilliant and then crash right down...
857
858 **Rachael:** It's like me I so badly wanted to go out – I wanted
859 to be an actress - my mum paid for me to go to acting school
860 and everything – I went for years and years and it as just like
861 (2) turned around and everything was gone – that's what it
862 felt like – felt like the whole world was just empty – it was
863 just me and everything came crashing down.
864
865 **I:** It sort of sounds like you have been robbed of something.
866 (**Rachael:** Yes. **Fiona:** Absolutely). I think they are both

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867 interesting points- where this approach perhaps doesn't really
868 affect the condition as such it's more your sense of self?

869

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

875

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

877

878 **Fiona:** I think so I mean I wouldn't go- I went on a new
879 deal for the disabled last time I was well enough to start work
880 again and they were useless. And I know they are looking at
881 doing a little more now. But I wouldn't trust them so far as I
882 can throw them- because I know so many people who have
883 been through new deal on one basis or another and they've
884 been sent to these training places and it's all so inappropriate
885 and they don't make any effort to understand individuals'
886 needs. (I: Right). It's just farmed out to these companies via
887 the job centre and nothing to do with the job centre and... (I:
888 Right). I'm an IT Consultant, "Well go and pull pallets
889 around in a warehouse then for six months for no money".
890 That sort of thing.

891

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892 **I:** So again there is something superficial about that about
893 that – superficially doing something but actually not listening
894 and not understanding.

895

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

897

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

901

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

905

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

908

909 **Rachael:** Yes it would be nice if society knew what it was
910 like. (I: Yes...). Yes obviously there's loads of ignorant
911 people – there's loads of different people in the world- in the
912 country- who have different ways of thinking about
913 everything. You know, down to the way a house should
914 look! But it would be nice if people were more aware of
915 what chronic fatigue syndrome is – I mean if the health care
916 doesn't know then who does know?

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917

918 **Pat:** We want to work and can't – a lot of people – don't get
919 me wrong – a lot of people on job seeker's can't find a job.
920 But some of them on job seeker's can work and they get
921 treated better.

922

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

926

927 **Fiona:** I think [name of therapist] and I are a little frustrated
928 at the moment with me- butting our heads against this wall of
929 she can't offer me any more treatment that we can't get any
930 further forward with what we are doing until I get erm three
931 or four problems sorted out. Like the chronic sinusitis, the
932 joint pains I suffer, my sleep problem – we are working on
933 the inevitable depression that you get from being incredibly
934 ill and getting absolute no sleep. But that's the only thing we
935 can do. We're here, we, I mean we both – it's nice that she
936 feels frustrated with me, but we are both very kind of head
937 against a brick wall at the moment erm. We've given up on
938 the graded exercise thing because it made me worse. (I:
939 Right).

940

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941 **Rachael:** Self-help can work! It can. To a certain extent

942 better than any doctor.

943

944 **I:** What would that involve?

945

946 **Rachael:** Just positive ways of thinking – like I was saying

947 about the bus. I am not gonna let it – it does take over my

948 life – but if I think it's not going to. I try and make my every

949 day be like normal. Sometimes it's not and sometimes I

950 overdo it – I mean I'm twenty and I wanna go out and go

951 clubbing and I can't do that. I know I can't do that- but self-

952 help is good you know – pacing yourself.

953

954 **Fiona:** You're doing it for you aren't you, you're not being

955 forced to do it by some great big therapist – you're doing it

956 for you. (**Rachael:** Yes – that's it). That's how you've got

957 to do it! If you don't do it for you- if [name of therapist] with

958 a cattle prod she wouldn't be doing any good.

959

960 **Rose:** It sounds as if- I saw [name of therapist] once, and she

961 said, "It sounds to me as though I can't actually be of any

962 help to you, because you're doing and have done all of the

963 things I would do with you. So I am going to pass you over".

964 But it sounds as if [name of therapist] has done like the

965 absolute best as far as not putting everybody into a category-

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966 because there are as many types of chronic fatigue as there
967 are people, you know, everybody had got such a different
968 experience- even just around here. I found that was the most
969 frustrating thing- of seeing a doctor and the doctor saying,
970 "You must do this", and sitting there knowing that that's not
971 gonna be right for me. [Laughs] And you're not listening to
972 me. You know sort of- I mean I've had one doctor say to me,
973 "You must you absolutely must stay awake all day and not
974 give in to going to sleep". Well if I did that I would fall
975 asleep at the wheel on the way to work literally. You know I
976 would kill myself because I wouldn't be able to stay awake.
977 Ehm, and that's been a frustrating thing is people thinking
978 that they know what's right for chronic fatigue sufferers in
979 this you know big, you know thing! And somebody like
980 [name of therapist] sounds as though she is working
981 individually with this is right for you and you saying about –
982 you know your running and whatever – and you saying
983 somebody told you to run and you saying "What!" [Laughs]
984 But yeah it sounds as though that's the starting point of
985 actually making progress for anybody isn't it? Of actually
986 being treated like an individual and being listened to.
987
988 **Fiona:** And by finding that suits you as well.
989
990 **Rose:** That's right. Is she from the Hospital?

991

992 **Fiona:** I did find it a little hard work- I usually have to tell
993 [name of therapist] two or three times if something's say not
994 right or I'd like to do something. But I think that's a good
995 thing in a way because it means that (3) say I felt something
996 was harmful and she knew I would pull out of it if I stuck at
997 it. She'd not say, "Give up" when I feel like giving up. I do
998 feel I have to push a little bit I mean I don't know if that is
999 normal – it's the first time – I've only been seeing her for
1000 about eighteen months – it's the first time I've had any
1001 treatment at all in any shape or form for ME. I don't know if
1002 that's how it goes – that's the only thing I've found I do have
1003 to push a bit – I do have to put my foot down a little bit.
1004 She's very good about it she doesn't kind of see me as a
1005 difficult patient-, which is something I feared very strongly.
1006 As if I kind of say I kind of being doing this for six months
1007 and I can hardly get out of bed now will she think, "Oh well
1008 this is stupid she's just not going to co-operate is she". She
1009 hasn't done – which is bloody good. (I: Right).

1010

1011 **Rose:** I really fear that to – that's interesting – I really fear
1012 that that somebody is going to think I'm a difficult kind of
1013 patient.

1014

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1015 **Fiona:** I had what you had with the doctor “Oh bloody hell
1016 not you again” sort of thing and you know she actually got
1017 quite nasty with me but fortunately I moved about three
1018 months after and I got a different doctor who just didn’t give
1019 a shit, you know just didn’t care you know – its just like “Oh
1020 its you again go and take paracetamol”.

1021

1022 **Rachael:** Oh I’m just like oh you get paid sort it out, I’m
1023 telling you I’m not well – I don’t give – I’ve got no sympathy
1024 at all. If somebody doesn’t want to help me I’ll tell them.
1025 You have to be firm that’s the only way I’ve ever learnt. Not
1026 to be aggressive but to be like you know, “I’m telling you I’m
1027 not very well listen to what I’m saying, you get paid for this,
1028 you have to listen you have to help me, you cant just fob me
1029 off with some antibiotics”. Cause I won’t let it. I’ll keep
1030 coming back – I will make an appointment every day if I
1031 have to and I’ll keep coming back until you help me. That’s
1032 the only way that sometimes you feel like you are getting
1033 through – see what I mean.

1034

1035 **Fiona:** [name of therapist] just helping me get to this stage
1036 because I am very, I have become very submissive in that
1037 way because I have just been everything from fobbed off to
1038 abused in trying to seek help I have just given up. (**Rachael:**

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1039 No you shouldn't). She's getting me back into stamping my
1040 feet a bit.

1041

1042 **II:** I mean it sounds like from what you are saying Fiona that
1043 there is something also in sort of those maybe all relations but
1044 you have talked about the professionals about sort of being
1045 able to be honest with someone and their being honest with
1046 you, like when stuff isn't working that you can actually say,
1047 "It's not working", and someone will be responsive to that or
1048 certainly receptive to it and maybe try and think okay right
1049 and not just keep going on. So I wondered is that true for
1050 other people.

1051

1052 **Pat:** She'll listen to anything- it might not be to do with ME
1053 – she sorts it out herself – with even family things – she'll ask
1054 me about you know if she thinks it could be something like
1055 that. It's not just me- she talks about my family as well and
1056 how it affects them. (I: So it's in context). Yes she gets
1057 involved, you know, not with just me you know.

1058

1059 **Fiona:** She's the first professional that I have been able to do
1060 that with I am not sitting scripting how can I go in looking so
1061 this person will give me treatment for the illness I'm going
1062 with and not just fob me off because it's ME or how can I
1063 look more ill. You know I can actually go in – she knows the

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1064 score and I can tell the truth – she is the first person I have
1065 ever come across ...
1066
1067 I: Yes there's something about being accepted then really
1068 isn't there that you can present as you are and you don't have
1069 to sort of do whatever you need to do to get help in other
1070 forums.
1071
1072 **Fiona:** Yeah make sure I haven't washed my hair for a
1073 couple of weeks and ruffle it up a bit before I go inside to
1074 look as if I'm really need of, in need. I've done that before I
1075 am ashamed of myself, [laughs] cause I'm no good at
1076 stamping my feet. I have to put [I: Right] it on.
1077
1078 I: I just want to go back to this thing about the fear of being
1079 perceived as difficult patient. How would you make sense of
1080 that?
1081
1082 **Rachael:** I think that's about from having bad experiences
1083 with doctors. (I: So do you think...) 'Cause you
1084 automatically think, yeah, their gonna think I'm a bad, erm
1085 you know, a difficult patient. 'Cause I've gotta try and
1086 explain from, you know what's happened in the past and do
1087 they understand? And can they really help me? Or do they
1088 think I'm being annoying and...

1089

1090 **Fiona:** Mmm. I think there's still an issue that when you go
1091 into a doctor and say, "I'm ill", and they'll go, "right take
1092 Paracetamol, go home and have a rest". You come back a
1093 fortnight later and you're still ill. And they're like, well what
1094 are they after? Are they jockeying for drugs? Have they got
1095 Munchausen's Syndrome? Are they jockeying for attention?
1096 (**Rachael:** [Laughs]. Yeah that's true!). Do they want tea
1097 and sympathy? Are they lonely, do they want a chat? Are
1098 they after anti-depressants to sell...

1099

1100 **Rachael:** Do you wanna see a counsellor- always! [Rose
1101 laughs].

1102

1103 **Fiona:** Right, right. It was hilarious I've had times where it
1104 has just been assumed that I have been after tranquillisers to
1105 sell, [laughs] which is nice!

1106

1107 **I:** So you have been judged. (**Fiona:** Yeah). I'm wondering
1108 whether there is something about the difficulty professionals
1109 face when they don't know what to do? (**Emily:** Oh
1110 absolutely!)

1111

1112 **Rachael:** That's why it's always put down to it being
1113 psychological; 'cause there's not enough research and

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1114 awareness into Chronic Fatigue Syndrome. [Sighs] People
1115 don't just get ill, I mean, there's got to be some underlying
1116 thing. [I: Mmm] I just think it can't be psychological, people
1117 love to fob it off as being psychological, for me, that's my
1118 experience, I'm not talking for everyone, but for me that's
1119 been my experience. [I: Right]. Some of it is okay, I think,
1120 some of it is, but some of it...

1121

1122 **Fiona:** I don't think you can have an illness like this and not
1123 have psychological problems!

1124

1125 **Rachael:** No. I mean some things are psychological, you
1126 know, when people go through trauma, and they get
1127 paranoid, and things, you know, bad things I can understand
1128 that it probably is psychological, a lot of it, and people do
1129 actually get over those. But I mean, nine and a half years, I
1130 think I would have been a bit bored of being [laughs] you
1131 know what I mean!

1132

1133 **Pat:** Well you would have pulled your socks up wouldn't
1134 you!

1135

1136 **Rachael:** Like I said, going to university, do you think I'd
1137 wanna jeopardise that for being on benefits!

1138

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1139 **Fiona:** I mean they act as if benefits is wonderful, it's like,
1140 it's bugger all, it's you know, I'm supporting me and a carer
1141 cause I'm not allowed a carer, so I've got to support
1142 somebody on my benefits, two of us. I've been sleeping on
1143 friends' settees for the last three years cause I can't have a
1144 carer and somewhere to live. You know, and they're like,
1145 "benefits are great, everybody wants to be on benefits 'cause
1146 it's so brilliant!" And it's like, who in their right mind, when
1147 you can get a job, you can get a basic minimum wage job and
1148 get three times as much per week as you would get on
1149 benefits just for showing up, not even having to do anything
1150 too difficult or strenuous...

1151

1152 **I:** Okay, there seems to be a difference between how you
1153 thought and constructed yourself before ME, and what you
1154 have had to think now? [Two participants murmur in
1155 agreement]. I guess you may be forced to reconstruct
1156 yourself?

1157

1158 **Fiona:** Yeah it's quite a painful process that forcing of your
1159 brain into that different shape. [I: Right] It feels, you
1160 almost melt and crash, and then pull up. You kind of, you
1161 end up, I mean I, I attempted suicide twice and then, at that
1162 point, it was like, "Okay, I'm ill, I can't get a diagnosis but I
1163 know I'm ill, and whatever anybody else says I'm not taking

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1164 the piss". And I know it's not the right either but, you know
1165 like, "I'm a bit depressed and I've got a brain tumour and
1166 they're not telling because I might top myself" you know,
1167 cause thought that might be it. You know I thought they
1168 thought "Oh she's got depression and if I tell her she's really
1169 ill, so I'll just say there's nothing wrong with her and send
1170 her home". I don't know, I don't think they really do that do
1171 they? Well I was seventeen and terrified, so, but I was a
1172 complete flat pancake at rock bottom, and you kind of
1173 reconstruct from there in the sort of ME shape, as it were.
1174 And yes I am ill and everyone else has got to bloody well
1175 cope with it. 'Cause I can't do a damn thing about it, and if
1176 they don't like it then they can piss off!

1177

1178 **Rachael:** It would be nice if there was a group you know,
1179 like this [**Rose:** Mmm], like this, but was ideal for everyone
1180 to get to. [**Fiona and Rose:** Yes].

1181

1182 **II:** I'm surprised there isn't?

1183

1184 **Rachael:** I think that would be good that would.

1185

1186 **Fiona:** I think there's a [Name of City] ME Group who, I'm
1187 a member of Action for ME, I try and keep up with the local
1188 groups and the current research- erm, and they've got no web

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1189 presence, they don't seem to be in any phone books, I've seen
1190 a poster somewhere but I can't remember where, one solitary
1191 poster. They seem to have such a low profile presence and I
1192 don't know whether that's deliberate or not, 'cause obviously
1193 people with ME, they don't wanna be inundated 'cause
1194 they'll be too knackered to cope with it.

1195

1196 **Rose:** Yeah! It's probably set up by private individuals that
1197 just want to have a support group so...

1198

1199 **Fiona:** And it costs money.

1200

1201 **Rose:** Yeah it costs money yeah, and it takes a lot of effort to
1202 advertise things, and erm... (**Fiona:** But if they...). And the
1203 energy's just not there to do it!

1204

1205 **Fiona:** But if they just contacted AFME [Action for ME],
1206 and just gave them the details they would put them on the
1207 website, and I get the 'Interaction' I get the bimonthly
1208 journal, and it would be in there, it would be get-at-able, and
1209 that would be free. I mean, I don't know, I mean it just takes
1210 somebody being a member of AFME and, being a member of
1211 the group as well.

1212

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1213 **Rose:** I just before, I mean, because I have to go at four
1214 o'clock but I think all the important things is this thing with
1215 psychological and the physical, because often doctors get to
1216 the stage where they say, "Oh it's psychological". Well
1217 actually, as Fiona said, you only have to be in pain for a short
1218 period of time before you've got psychological problems
1219 [laughs]. You know, you have got problems, you either got
1220 depression or, or, you're wrapped up in some psychological
1221 thing. And I think that's frustrating that doctors do seem to
1222 actually negate everything that's gone before, how you got to
1223 where you are and say, "Well you do have psychological
1224 problems with it". (Fiona: Yes). Okay I do, but I started off
1225 with pain, not being able to get out of bed and all of that. But
1226 for me, being here in [name of building where Rose has
1227 therapeutic sessions], as I haven't seen [name of therapist that
1228 has seen Fiona and Pat], well actually that's, for me nice to
1229 have somebody that appreciates that, "Yes we do have
1230 psychological issues to work through and I also know, I'm
1231 listening to you, that you have all that pain and everything
1232 else, and possibly that started first, or maybe, shall we look
1233 and see whether there was anything before that? There might
1234 not be, but lets look at it". It's that openness which for me is
1235 important.
1236

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1237 **I:** So important that someone is honest (**Rose:** Yes) with you
1238 about their position.

1239

1240 **Rose:** That's right. And them not saying, "Well I'm
1241 suggesting that this is how it happened", because they don't
1242 know, they have got no idea, but "let's explore it together".

1243

1244 **Fiona:** Well you get ten minutes for a doctor's appointment,
1245 what can you tell them in ten minutes.

1246

1247 **Rose:** Exactly, yes. Because you want to tell them what
1248 happened ten years ago, don't you?

1249

1250 **Fiona:** I've been through all sorts of stuff symptoms-wise,
1251 and I'm still getting new symptoms, and knocking old ones
1252 on the head, I mean, it's still changing. (**Rose:** Mmm) And
1253 it's been eleven years now, nearly twelve!

1254

1255 **Rose:** And you can't get any help from a doctor when you're
1256 going in with today's symptoms because that's not gonna
1257 help at all, 'cause it has to be seen in the whole picture.

1258

1259 **Rachael:** It needs to be holistic yeah.

1260

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1261 **I:** I guess as well it's also difficult to convey the whole
1262 picture to the doctor, because of yes, the limited time frame
1263 but also because of the cognitive effects of having CFS.
1264

1265 **Fiona:** Even writing it down don't help cause the letters
1266 swim in front of my eyes, I can't read it. (I: Right). 'Cause
1267 I've developed a bit of a panic disorder since the last relapse,
1268 what with one thing and another, and I was so high by the
1269 time I went to the doctors I can't read the bloody thing.
1270

1271 **I:** Okay, I don't particularly want to continue the group
1272 discussion without Rose. So is that okay with everyone that
1273 we still finish at four, I know it feels a bit rushed [participants
1274 nod in agreement]? I would like to thank you all for coming I
1275 know it has been a long way for some of you. I have found it
1276 very interesting today, and hope you have also got something
1277 out of it.
1278

1279 **Pat:** I think it's because we all want something done about it
1280 we've come.
1281

1282 **Rose:** You're right [other participants say "yes"]
1283

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1284 **Rachael:** I don't mind if you ever want to, again talk to me.

1285 (**Fiona:** Yes me too). I'd be happy, more than happy to help

1286 you with your research for Uni, and stuff like that.

1287

1288 **I:** Thanks very much. Is there anything people want to say

1289 briefly, bearing in mind the time, is there anything burning

1290 that you feel you had not had the opportunity to talk about

1291 today [looking at Collin].

1292

1293 **Fiona:** [Laughs with Collin] you're on the spot again!

1294

1295 **I:** [Laughs]. Okay let's start at the other end of the circle.

1296

1297 **Fiona:** I've pretty much spat out the couple I wanted to, I'm

1298 okay.

1299

1300 **Pat:** I think it's done us all good to be here today!

1301

1302 **Collin:** I think so too. (**Pat:** Yeah).

1303

1304 **Fiona:** Yes, I've never met anyone else with ME before

1305 [laughs].

1306

1307 **II:** That's something in itself isn't it.

1308

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- 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
- 1312 you the information? [All participants indicate that they
- 1313 would like this].
- 1314
- 1315 **Rachael:** I do know one, it's AYME [Name of organisation]
- 1316 they only deal with people up to twenty-five...
- 1317
- 1318 **Fiona:** Yeah, I'm aware of them, and they're excellent but I
- 1319 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
- 1324 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,
- 1329 erm, Chronic Fatigue Syndrome [person's name] and he did
- 1330 get better! And he had for seven years.
- 1331
- 1332 **I:** Okay, so there's hope? [Facing the remaining participants
- 1333 that had not spoken]. Is there anything that you wanted to

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- 1334 add or say differently? [Participants shake heads] Okay well
- 1335 thanks again for coming.
- 1336
- 1337 **Rose:** Thanks it was good meeting you all. [Remaining
- 1338 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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1 **I:** Basically what the group discussion is focusing on is your
2 relationships with the Health Service, so that includes GPs
3 and your therapeutic relationships that you've had – that's
4 with [names of therapists].

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

12

13 **Kay:** You can't please everyone can you – it's difficult.

14

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

20

21 **Kay:** That seems fair enough. (**Kerry:** Yes that's fine.

22 **Mark:** Yep).

23

24 **I:** Yes, okay. In terms of ground rules, because this is a
25 confidential group, I think we need to sort of protect each

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26 other really, so what's talked about in here doesn't go outside
27 the room. **Mark:** Sure. (**Kay:** That's fine. **Kerry:** Yes).
28 Have you got anything else that you would like to add to
29 that? (**All:** No).

30

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

41

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

48

49 **Kay:** I found it quite helpful talking to [therapist's name]
50 because I think people perceive you differently – I don't

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51 know whether that makes sense. Your friends look at you
52 sometimes as if, because, if you've got a broken leg they can
53 see what it is, but people find it hard to know what is wrong
54 with you, and to understand that you are in pain, and because
55 you don't look ill [Mark: Yes] that's the hardest thing isn't it.

56

57 **Kerry:** Because they can't see something.

58

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

62

63 **Mark:** There's a bit about sympathy and understanding.
64 You just want to be taken seriously.

65

66 **Kay:** And I think the GPs are absolutely disgraceful.

67

68 **I:** Right and that was your experience with it?

69

70 **Kay:** Yeah. Because I was diagnosed with it about 6 years
71 ago, and my doctor sort of pooh-poohed it – I've got another
72 doctor in the practice now and she is quite good with it
73 because her sister has got fibromyalgia. (I: Right). But I
74 went one day when I was really at a low ebb, and my doctor,
75 who we know personally as well – he'd had a bad day

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76 obviously, and he said I'm really knackered today Kay, I've
77 been doing the garden all day – do you think I've got
78 fibromyalgia? And you could just turn round and think
79 "What!" [Sighs].

80

81 I: Yes that's dismissive isn't it?

82

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

87

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

90

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

97

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

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101 **Kay:** It's like a cop out. (Mark: Yeah)

102

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

114

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

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126 sort of general life, got it - one was an Ironman tri-athlete, so
127 not just like a normal tri-athlete. I was a long distance runner
128 and a semi-professional footballer, you know. Most the
129 people I know are not naturally lazy – that's the thing that
130 annoys me is that they are not lazy they are people that
131 actually did the opposite [all agree] and that didn't rest when
132 they had virus and things like that. (I: Right).

133

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

135

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

142

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

146

147 Kay: It's the same thing isn't it? No – they are hard working
148 like you were saying [looks at Kerry] like the exams and
149 that... (Mark: Yes)

150

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151 **Kerry:** Well I got it when I was doing my GCSEs.

152

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

154 and...

155

156 **Mark:** I think it was, when it got, I don't know about going

157 back before the seventies but I remember in the eighties it

158 was Yuppie Flu. (Kay: That's right yeah.) And that's kind

159 of, well, well that's not going to do any condition any favours

160 is it! 'Cause you know, people aren't particularly

161 sympathetic towards yuppies you know – "a load of rich

162 people are getting ill – oh well that's their problem," sort of

163 thing. But, but that also kind of proves that it's people who

164 are burning themselves out in a way. And personally I mean

165 I was working, I was doing a long commute – I was working

166 at [name of newspaper] and you know, in the mid-nineties I

167 was playing semi-professional football, I was playing Sunday

168 League Football – I was doing 5-a-side – my life was just

169 absolutely chaotic.

170

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

172

173 **Mark:** No I wasn't! But then I – you know – and then I had

174 to go through like when I'm in my sessions with [name of

175 therapist], one of the things she put to me was that, you

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176 know, psychologically would you be wanting to avoid. You
177 know, cause she was going through all the, you know, all the
178 psychological aspects of it. And you know, is there anything
179 you want to avoid, you know, by not working. Do you enjoy
180 not working and you know – all these kind of things and I,
181 you know I much prefer my old life to my current life. (I:
182 Yes, yes). And so you know and so there are certain things
183 that I gain now and I don't have certain pressures and
184 responsibilities you know but there are other things that are a
185 hell of a lot worse.

186

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

189

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

197

198 **Kay:** It's harder for you cause you haven't got (2), you can't
199 have the drives that they would have, can you – you know
200 what I mean?

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201

202 **Kerry:** Oh maybe you have mentally but you can't manifest
203 it (Mark: Yeah).

204

205 **Kay:** Yeah, I didn't phrase that very well, but you know what
206 I mean.

207

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

212

213 **Mark:** It affects every aspect of your life...

214

215 **Kerry:** It does, doesn't it? Yeah.

216

217 **Mark:** And that reflects on your self-esteem, so then sort of
218 if professionals aren't you know taking it seriously then -
219 you know I'm like...

220

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

222

223 **Mark:** No, I mean I went, I spent, I first noticed things
224 weren't right in the early nineties. Ninety-one I can first
225 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

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251 Occupational Health Therapist by that Fire Station in [name
252 of town]. And, erm, it was a GP who sort of went in there to
253 help out, and she was brilliant – she kind of was the first sort
254 of GP who had taken me seriously. (I: Yeah.) I said, “Oh
255 can I join your – you know, can I come and join your
256 practice...” [GP] “Oh well I can’t and I work on the other
257 side”, and you know it’s that kind of thing. You know, you
258 don’t want, you know don’t want to sort of con anybody, but
259 you just want someone who takes you seriously

260

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

266

267 Kay: They think they will throw a few anti-depressants at
268 you, and think, “well you go away and sort it out yourself,”
269 sort of thing. But I was lucky because, do you know [name
270 of therapist]? (I: No.) She works with [therapist’s name] and
271 she’s a friend of my daughter’s. Because I was down about it
272 she said, “Have you thought about going to see, erm,
273 whatever they’re called at [name of Hospital Department]?”
274 (I: Yes). You know where I went to see [name of therapist].
275 I went to my doctor and said, “Could you refer me, because I

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276 have been advised to do this, and it might help me because

277 we've tried everything else." He said, "No you can't

278 possibly do that, that's not in our remit to send you".

279

280 I: The GP said that?

281

282 **Kay:** Yes. So err, I went back and, went and saw her and

283 said, "Look he said that." And luckily, she being a friend of

284 like our family and my daughter and everything, she went

285 down to the doctor and said, "Look will you refer Kay to the,

286 not to me because I know her, and she perhaps won't want to

287 talk to me, but to one of my colleagues." So he did and that's

288 the only way I could get any help

289

290 I: So that's really marginalised isn't it, (**Mark:** Hmm),

291 where the GP won't even listen to you to refer you on.

292

293 **Kay:** Oh yes, "Can't do that", you know, "they don't do

294 that." And then you feel - luckily otherwise I would never

295 even get to see [name of therapist]. It's still like, you had to

296 do it all yourself. (I: Right). There doesn't seem to be the

297 help out there at the grass roots level. Once you get to

298 someone like [therapist's name] and then you ring up, you

299 find it is really being taken seriously. But if you don't

300 actually get to see someone, you think well nobody cares.

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301 **(Mark: Hmm.) Don't you? It's like being on an island**

302 **sometimes, do you feel like that? Sort of, however you feel**

303 **on the day – some days you feel a lot better than others, but**

304 **sometimes you feel quite alone.**

305

306 **I: Yes I imagine it is very isolating to feel like that. In terms,**

307 **how did your families relate to it, or the people you were with**

308 **at the time?**

309

310 **Kay: Well at first I think, mine started that, we had worked**

311 **so hard for years and years, and then one Christmas I went**

312 **down with the flu. And I really wasn't very well. And I kept**

313 **getting these pains in my stomach, and they thought I had**

314 **bowel cancer. (I: Right). Actually I hadn't, but I had to go**

315 **in for a big bowel operation. And I came home, and then I**

316 **never got out of bed for weeks and weeks and weeks. And I**

317 **just couldn't pick up, and in the end they diagnosed**

318 **fibromyalgia. But it was (2); in the meantime you think that**

319 **it's all in your head. I'd had this bowel operation and then I**

320 **was supposed to then get well, in my eyes... (Mark: Mmm)**

321 **and make me better, but I just wasn't getting any better! I**

322 **hadn't actually got cancer but I'd got something wrong with**

323 **my bowel anyway. So I had this huge operation, but after**

324 **weeks and weeks and weeks I still wasn't getting better, and**

325 **in the end it was diagnosed as fibromyalgia.**

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326

327 I: And what did your husband – was he supportive?

328

329 Kay: Oh he was marvellous! He really is supportive, but it
330 was hard for him because he was running a pub on his own
331 virtually, and there's me lying upstairs, sort of not moaning
332 but sort of not being able to help. I used to cash up in bed –
333 you know sort of do my bookwork in bed and things like that.
334 (I: Yes.) But once someone has diagnosed it you have got a
335 feeling that you are not absolutely going mental. [Mark
336 laughs]. (I: Right). Cause you do feel like that. Did you feel
337 like that? (Kerry: Well...). "Well is it all in my mind?"

338

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

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350 trying to get out of my exams and trying to get out of
351 schoolwork.

352

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

360

361 Kerry: I think maybe they just see the advantages not the
362 disadvantages. They don't realise, that they sort of see you
363 and you're maybe okay, and then they don't see you when
364 you're at home and you're collapsed on the bed or whatever.
365 They only see that you are getting out of, you know, maybe
366 work or schoolwork. I mean I couldn't participate in my
367 lessons. I had to sit downstairs because I couldn't climb the
368 stairs, and only could come in for a couple of hours a day. So
369 they saw me going home at lunchtimes and they just had to
370 go you know, and do their lessons for the afternoon so...
371 (Mark: Yes, they probably resented that). I could see it from
372 their point of view, especially as I got it, you know, when I
373 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.

376

377 Kay: They don't understand do they?

378

379 Mark: I think – I've kind of worked in offices and there's a
380 culture of people, you know who pipe up, "Oh I've not had a
381 sick day in 5 years." (I: Right yeah.) Things like that,
382 "Look at me, I'm great," and you know, and it's that [gasp]
383 you know. I also think that this society now is, if you can't
384 see anything you won't, you won't believe it, you know what
385 I mean. (I: Right. Kerry: Yes). It's a cynical society and,
386 ehm, and I, I even think that, you know, about some people –
387 you kind of find yourself thinking, "are you putting that on?"
388 and you think, "no that's a terrible thing to think." But I
389 think that's a natural thing, if you can't see something wrong
390 with something, so I can understand to a degree, I mean had,
391 you know, I was in a sort of bad situation my family were
392 down in London and they were quite understanding about it.
393 But my wife at the time (2) was from a family, where she
394 used to work for her family, and she was never allowed to be
395 ill. (I: Right.) You know, her family would never give her
396 permission to be ill. At the point, at one stage (2), her mom
397 was shouting at her saying there was no such thing as ME or
398 Chronic Fatigue Syndrome. You know, and so her entire

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399 family didn't believe it existed, they all thought I was a
400 malingerer, even though I was then trying to do, you know,
401 until you try and do more to prove that you're not and you
402 end up doing too much. (Kay: That's right. Kerry: Yes.)
403 Then you end up getting ill.
404
405 Kay: Yes that's right, it's a vicious circle.
406
407 Mark: Yes and the stress is that.
408
409 Kay: And then saying it messes with your head. (Mark: Oh
410 definitely!) Doesn't it!
411
412 Kerry: You think, "Am I making it up?"
413
414 Kay: I used to think it was all in my head at one time. I used
415 to think, if I'm in this much pain, why can't they tell me
416 what's wrong with me. And you find that your friends don't
417 invite you out any more, because you have to cancel so often,
418 that in the end they don't invite you. (I: Right.) And it, it
419 must be harder for you, because you are so young [looking at
420 Kerry].
421
422 Kerry: Well it was hard yes.
423

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424 **Kay:** Because you have missed time when you should be
425 going out and letting your hair down. (**Kerry:** Mmm.) You
426 know, that's hard when you are sort of leaving school, you
427 should be out at night going and getting drunk, and doing
428 silly things and going on holiday with your mates and...
429
430 **Kerry:** Yes I think the hardest thing is watching other people
431 and...
432
433 **Kay:** Do it - that's right! (**Mark:** Yeah).
434
435 **Kerry:** They're carrying on with their lives and going out
436 somewhere and I keep getting held back.
437
438 **Kay:** Yeah! I find it when, we used to walk a lot, and we
439 used to go out and dance, you know. And now, we go
440 occasionally perhaps a golf club dinner with [female name]
441 sister and her husband, and they are all up jiving and dancing
442 and we get up and have the last dance – a slow dance. I can't
443 get up and jive with them, and I'm not jealous, but you just
444 wish you could do it with them. You know what I mean? (**I:**
445 **Yes, yes.**). It is hard, it's like picking my grandchildren up –
446 I can't – the boys, my little grandson is only a year and trying
447 to pick him up – I can't do that. I could probably lift him up

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448 to put him on the settee, but I couldn't hold him in my arms
449 he is too heavy for me. It's the silly things that hurt the most.

450

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

457

458 **Kay:** Things you miss doing with him.

459

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

470

471 **Kay:** It knocks your self-esteem again doesn't it!

472

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473 **Mark:** So that, and all that was, a very helpful part of the
474 process was coming in seeing [therapist's name] and talking
475 about (3) Because it just happened that I went, I was booked
476 in to go for the ME I think I must have seen [therapist's
477 name] it might have been [therapist's name] with [therapist's
478 name]. (**Kay:** That's [therapist's name].) [Therapist's
479 name] rings a bell, the name [therapist's name] rings a bell
480 but also I saw [therapist's name]. I don't know if it was at
481 different times, I can't remember. And so I was booked in to
482 have the ME treatment, I think it was going to be Cognitive
483 Behaviour Therapy or whatever it, but at the time my wife
484 had been, you know, I was having to move out of my home.
485 I had nowhere to live, you know, I was miles away, I lost my
486 friends, cause my friends were my wife's friends. You know,
487 everything went just completely crazy, and so I ended up
488 coming here and more or less just having, you know, more
489 like a counselling session and just chatting and... (**I:** Ehm.)
490 I did find it brilliantly helpful when I think. (**Kay:** I do.) I
491 don't know what, I don't think I would still be here if it
492 wasn't for that because, just because everything was going,
493 you know, every area of my life, you know, was gone.
494
495 **I:** Yes, you experienced many losses.
496

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497 **Mark:** Yes, yes and I didn't know, I wouldn't have been
498 able to cope I don't think otherwise.
499
500 **Kerry:** Yeah I had it, when I was referred, it just happened,
501 it happened at a time when I was feeling really bad, and
502 because I had a massive relapse after my A-levels. But I was
503 feeling really severely depressed. I didn't actually see
504 [therapist's name] first of all. I was referred, erm, I had a
505 psychiatric nurse came round my house. (I: Okay.) Erm,
506 that was helpful, but it was obviously she did graded exercise
507 with me to start with. But I did feel that nothing was done in
508 depth that, you know she did some graded exercises with me.
509 I had to fill in diaries and things – my activities and things
510 like that – but I never felt anything was followed through
511 with. (I: Right.) Earlier I mentioned something about CBT
512 because it had been; they described something to me, what
513 the treatment involved CBT and graded exercises. I said, you
514 know, “am I going to be having CBT?”, and she said, “Well
515 if you want it, yeah, we'll go through with that.” And she did
516 give me the diaries to fill in about, you know, thoughts - you
517 know, diaries every day. (I: Right.) But she never followed
518 through with it, and I never really had any CBT in the end
519 [laughs].
520

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521 I: Right yes, if you are filling things in you want something
522 to happen with it.

523

524 Mark: Yes, what's the point otherwise?

525

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

538

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

542

543 Kerry: Maybe a bit of both. (I: Right.) I didn't, I felt, yeah,
544 it was paying lip service to the service. (Mark: Mmm. I:
545 Sure.) And it was sort of, you know, you've got this Chronic

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546 Fatigue Clinic, you've got this person coming round your
547 house, but I didn't feel it was getting anywhere. I felt at
548 times she was so neutral, you know you sort of talk to her
549 about something, and she would be so impartial that you
550 would never really get anywhere! You know, you would be
551 maybe asking her opinion, and she would sort of say, "If you
552 want to do that do it and if you don't then that's alright."
553 And I think she felt so afraid of saying the wrong thing that
554 she didn't want to say anything at all. (I: Okay right.)

555

556 **Mark:** That's quite an interesting thing, jumping in, there
557 was quite a interesting thing I found about when I saw
558 [therapist's name], is that some weeks I'd go she would know
559 to listen and (1) (I: Yes.) you know, it's like something
560 absolutely crazy has gone on in my life a few days
561 beforehand, you know, because all my life was going mad in
562 between while I was seeing her. And so some weeks I would
563 turn up and I was in complete different headspace than other
564 times. Then other times she would challenge me, and that
565 was kind of, it wasn't just, you know, it wasn't as you say a
566 neutral sort of passive thing. (I: Yes.) Sometimes she, she'd
567 be, she would you know she would really push you, and it
568 would be damn tough, and she would say, you know,
569 "Sometimes you will leave here hating me", she'd say,
570 because she would try and get to the root of the issue and do

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571 things like that. And I thought that was good, you know, that
572 you felt like you was, you'd been put through, you know, you
573 had been made to think about things. It certainly helped me
574 look at, look at myself differently and change a lot of my
575 attitudes, and I think it helped me make me a better person
576 afterwards. I've still got ME, and I still have the same
577 physical problems, but mentally I deal with it in a different
578 way. (I: Right.)

579

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

585

586 **Mark:** It sounds like the right word.

587

588 **Kerry:** It sounds like self-esteem! (**Mark:** Yeah but just...)

589

590 **Kay:** Yeah, but, but I don't feel confident in myself even
591 now, but I feel as though I'm...

592

593 **Mark:** I think if you suffer then you can understand. (**Kay:**
594 Yeah, Yeah.) You can be more compassionate.

595

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596 **Kay:** Yes that's it! You're more compassion with a lot of
597 people. But I don't think, like when you said, there's a lot of
598 negativity obviously when you were talking [looks at Kerry]
599 to her she wasn't giving you anything. It's as though they are
600 frightened to give you advice.

601

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

606

607 **Kay:** They're so frightened of being sued or whatever aren't
608 they!

609

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

616

617 **I:** It sounds like she needed some support really.

618

619 **Kerry:** Yeah, to me more, you know, aware and...

620

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

629

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

638

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

641

642 **Mark:** I don't know, you said about being a pest, but I
643 thought that was quite an interesting thing. Cause I feel, like
644 I go to my doctor and I think he looks at me and thinks I've
645 got a hypochondriac here. (Kay: Yeah.) You know, because

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646 I used to, everyone used to say, "What's wrong with you
647 again?" because I spent years...

648

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

650

651 **Mark:** You know I spent eight active years with ME. (**Kay:**

652 **Yeah.**) Trying to drink more coffee to get through the day.

653 (**Kay:** **Yeah.**) Trying to take more, you know, before I did

654 sport, I would be drinking two cans of red bull because I –

655 just to get going (**Kay:** **Yeah.**) – I could not, you know, and

656 all these things and then you would feel awful. When I'd go

657 to the doctor about something and, or I'd have a headache

658 and I'd be popping pills and people would be like, "What's

659 wrong with you" – you know and you know – and I'd try not

660 to go to the doctor unless I can't really avoid it.

661

662 **Kay:** Yes 'cause your GP is, I feel, no I find is no help to

663 you at all.

664

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

666

667 **Kay:** All they want to do is just repeat your prescription –

668 that's all I go for.

669

670 **Mark:** Yeah that's all, yeah.

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671

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

683

684 **Kay:** Do you think they don't really understand us?
685 Probably you do [looks at investigator] because you're
686 looking into it, do you know what I mean? But a normal GP
687 doesn't understand how you feel, not in any way at all.

688

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

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696

697 **Kay:** Yeah but your doctor's supposed to try and understand
698 aren't they!

699

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

703

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

708

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

711

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

715

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

717

718 **Kay:** No, no, this is it.

719

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720 **Kerry:** Like I say there's blood tests for it, it's tangible you

721 can see it.

722

723 **Mark:** But they're - aren't they starting to find there's more

724 sort of physical abnormalities with ME, or more, sort of like,

725 is it the EPA (XXX) in the brain? That there's lower levels

726 of. Erm, I've now ended up looking up, I don't know, this is

727 a weird thing that's apparently been round a while, that

728 people with ME have less blood. Have you heard that?

729

730 **I:** There's so many different theories, (Kerry: Yes.) but yeah

731 I have heard something about blood platelets.

732

733 **Mark:** Yes things like that.

734

735 **Kay:** There's a doctor in New Zealand who says that, now I

736 don't understand this altogether but, like the platelets in your

737 blood they're supposed to be oval aren't they and they're

738 flattened out more when you've got fibromyalgia. So the

739 oxygen doesn't get to your muscles like it would do if you

740 were normal.

741

742 **Mark:** But the more stuff like that is found out, the more

743 that, you know, they can actually look and say, "You know

744 look actually we checked..." (Kay: Yes.) Because wasn't

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745 multiple sclerosis the same in the sixties – I remember
746 somebody saying about that. At first, they couldn't find
747 anything wrong with people with MS. But now you hear
748 about MS and you think well that's a serious (2). You know,
749 you could live next-door to somebody who had MS, you
750 know, and you know, what I mean. Oh she's got a proper
751 illness and I've got ME, you know [laughs].

752

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

757

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

765

766 Kay: That's right, because years ago, I'm not saying my
767 mum because she was a nurse, but most people, the
768 generation before me never questioned a doctor because they
769 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.

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794 **I:** So is that what happens in your relationship with the GP?

795 **(Kerry and Mark: Yeah.)** In that their disempowerment is

796 projected on to you?

797

798 **Mark:** Yeah. Well they are going to get; they are going to

799 get sense of failure at the end of a discussion – because they

800 can't help you know.

801

802 **Kerry:** Yes like, "Oh what can I do - I can give them anti-

803 depressants and err." **(Mark: Yeah.)**

804

805 **I:** Or I can choose not to believe in the existence of the

806 illness. **(Mark: Yeah, yeah. Kay and Kerry: Yes.)**

807

808 **Mark:** If they say that, if they think that, it's easy to say,

809 "Well we think you're a hypochondriac." Then they've not

810 failed, have they, because it's like erm.

811

812 **I:** There's a label – there's a diagnosis!

813

814 **Mark:** Yes there's a diagnosis, yes, yes the diagnosis is "I

815 can't do anything with this person they've invented

816 everything." So it's much easier to label somebody a

817 hypochondriac, and you know.

818

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819 **Kay:** I think this is why we have so much trouble with our,
820 our minds, about it, because the doctors make you feel that
821 way. You make yourself feel that way. Your friends make
822 you feel as though you are not like them or not like you were
823 because you know. (I: Right.)

824

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

841

842 **Kerry:** I think the degree of empathy and understanding of
843 the illness, as well as, you know, the psychological

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844 understanding of how it affects you emotionally. 'Cause
845 obviously ME isn't just a physical thing is it – it does
846 damage, you know, it knocks your self-esteem, it knocks
847 your confidence and...

848

849 **Mark:** I think because you get depressed from it, you then
850 get labelled, you know it's like "Oh you're just depressed"
851 because there are certain similarities with depression.

852

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

860

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

863

864 **Mark:** 'Cause I spent ages training harder to try and get
865 fitter. (I: Yeah.) And thinking "Well, hang on a minute why
866 am I feeling ten times worse" – I went through that stage of
867 denial – which I read about as in Dr Shepherd's book, you
868 "know, on ME. And he'd said that he went through the stage

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869 of going for runs to try and beat it, and I did that, I did all that
870 and just ended up getting worse and you know. But the
871 depressing thing is I knew that I wasn't depressed when I was
872 - you know, I got ill during, you know, when my life was
873 going swimmingly. And you know, and it was only
874 afterwards that I then got gradually got depressed, and
875 realised that I got seriously depressed. But I kept, you know,
876 I kept sort of denying to myself that I was depressed -if that
877 makes sense, because I didn't want to be labelled as
878 depressed. (I: Yes.) Because I knew that wasn't, you know,
879 but obviously if your life's, if everything in your life goes,
880 you know, is turned upside down and turns pear-shaped
881 you're gonna be depressed. Anyone with an illness would be
882 depressed.

883

884 **Kay:** And when you say you've got depression that
885 sometimes, with some people, brings out another stigma
886 doesn't it?

887

888 **Mark:** Well yeah. It's again, how can you prove that you're
889 depressed, how can you see...

890

891 **Kay:** That's right, you know, I've got a sister-in-law that
892 says she's never ill, [corrects self] never well, but there's
893 nothing really wrong with her. She can shop seven days a

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894 week, (Mark: Yeah.) go out for lunch and goes out ever such
895 a lot. And when I said to her I was going to see [therapist's
896 name], she said, "Oh where are you going to see her?" And I
897 said, "at the [name of Psychiatric Liaison Ward]." She said,
898 "Ooh, you ought to be careful there, that's where all the
899 nutters are." [Mark laughs]. And you think, "That's another
900 one." You know, another negativity. (I: Mmm.) And in the
901 end you don't tell people where you're going.

902

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

904

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

912

913 **Mark:** I try not to think, don't know, I don't like, the,
914 depression and mental illness – you think of mental illness
915 and you think of sort of I don't know...

916

917 **II:** Some severe mental illness?

918

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- 919 **Mark:** Yeah. You think that's slightly – you know
920 depression can be severe if you have it bad enough, but, it's,
921 as you say you, think of more insanity rather than you
922 know...
- 923
- 924 **Kay:** Depression and anxiety. Yes I used to have anxiety
925 attacks.
- 926 [One member of group stops the discussion to go to toilet.
927 Facilitator suggests a break]
- 928
- 929 **Kerry:** I think on the side of depression there is the tendency
930 to focus on what you can't do, more than what you can do.
- 931
- 932 **Mark:** The best thing is to concentrate on what you can still
933 do – if you go down the route of what you can't do you (2)
934 you know.
- 935
- 936 **I:** But it almost seems, from what you are saying, that you
937 have to go down the route of what you can't do to get to that
938 position of focusing on what you can do.
- 939 [All agree]
- 940
- 941 **Kay:** It doesn't happen over night, it happens over a series of
942 years doesn't it? [All agree]. I was really upset because I'm
943 football mad. And I thought, "Well I shall never get to see a

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944 live game again. I'll be watching it on the telly." But we've
945 found a bus, we go to [name of neighbouring city], I
946 shouldn't say this really in [name of city] but we go to [name
947 of neighbouring city] to a pub. We go on a bus to right
948 outside the stadium, and back on it again – so we found a
949 way to go to the football.

950

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

964

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

968

Kay: See you do find a way of it don't you.

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969

970 **Mark:** Yeah, but there's certain things like if I go out, I go

971 out for a quiet...

972

973 **Kay:** I can't go to away games. (**Mark:** No.) Because I

974 don't know whether I will be able to get near enough to a

975 stadium to get there. Because it drops you off right outside

976 the gate where I go in.

977

978 **Mark:** Yes that makes it...

979

980 **Kay:** And it's wonderful, you know. And I don't go every

981 week because I don't always feel well enough to go. (**Mark:**

982 No.) But then one of our relations in [name of neighbouring

983 city] will take my ticket, which is great!

984

985 **Mark:** Yes it's tempting. I mean I still go out. You know a

986 lot of evenings I won't feel like going out. But I still lead I

987 still lead a pretty, you know when I'm at my worst, yeah you

988 know, I've never been so bad that I'm bed-bound - I can

989 always kind of get about. But there's, you know, I have

990 times when I find it hard, in the evening I feel pretty poor but

991 you know, I can go out once a week, you know, but I can't go

992 night clubbing, I can't drink, you know if I drink I get ill...

993

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- 994 **Kay:** I can't take me tablets if I drink...
- 995
- 996 **Mark:** So, there's all sorts of different things...
- 997
- 998 **Kay:** So I'm the driver now you see, which is great for
- 999 everyone else, isn't it, so yeah you're not that useless are you.
- 1000 **[All laugh]**
- 1001
- 1002 **I:** Great for everyone else but not for me! (**Kay:** I don't
- 1003 mind.)
- 1004
- 1005 **Mark:** It's nice to have a use I suppose, at least you feel
- 1006 useful.
- 1007
- 1008 **I:** So you have got a role? (**Mark & Kay:** Yeah.)
- 1009
- 1010 **Kay:** Yeah, they all have a drink, we go quizzing on a
- 1011 Thursday night. And I can sit and do a quiz so that's
- 1012 something I would never have dreamt of doing years ago but
- 1013 I enjoy it.
- 1014
- 1015 **Kerry:** But like you say it is really tough on your social life.
- 1016 (**Mark:** Yeah.) Because I basically have a very limited
- 1017 social life because I can't sort of go out in the evenings and
- 1018 go out drinking.

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1019

1020 **Mark:** Yeah. Have you not got any friends that can take

1021 you, you know, that you can find things to do that...

1022

1023 **Kerry:** Yeah. I was going to say, I have found things to do, I

1024 mean I have started doing some voluntary work. (I: Right.)

1025 With young people and, and I go out with friends in the

1026 daytime if I can. They tend to drive me, you know,

1027 somewhere so that I don't have to walk very far. Yes you do

1028 that and you have to sort of make compromises. (**Mark:**

1029 Yeah.) So you go out for an hour instead of three.

1030

1031 **Kay:** That's it. When I get home from the football I get on –

1032 Frank's bought me a recliner chair, and I get on that with the

1033 remote control turn the telly on and I'm asleep, you know.

1034 You sleep through the evening because you've been out in

1035 the afternoon. (I: Mmm.) It's like driving, I don't feel

1036 confident enough to drive – this is the furthest I've driven for

1037 a long time.

1038

1039 **Kerry:** I can't drive any more than about three or four miles

1040 at a time without getting too tired so, I tend to, you know. I

1041 do drive into [name of Town] which is only just up the road,

1042 but I can't drive any distance, so you know it's really difficult

1043 to get anywhere you know.

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1044

1045 **Mark:** Your life kind of shrinks down in that sense doesn't
1046 it? Everything gets more local and that can be quite, I know,
1047 I got my own car now but when I was with my wife we had
1048 one car and she was out working and she'd have the car. So
1049 I'd be stuck at home all day and if I wanted to go out
1050 anywhere I would have to walk. (I: Right.) Then that was
1051 waste... (Kay: And you can't...) Well yes I can still walk a
1052 mile a day not too bad. Anything above that, and I'm you
1053 know I used to be, when I was first diagnosed – because I had
1054 been playing football up to the point I was diagnosed – I used
1055 to have to do 4 or 5 miles walks and that would be shattering.

1056

1057 **Kay:** The one thing that [name of therapist] was really
1058 helpful with – she said, "Why are you worried what's gonna
1059 happen?" and I'd say, "Well I don't (2) nothing I suppose
1060 really." But you think "Supposing I can't get back to the car
1061 and I don't feel very well", and you think...

1062

1063 **Mark:** The thing is not being in control of your own energy.

1064

1065 **Kay:** That's right! That's what it is! Yes it's the control
1066 isn't it?

1067

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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

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1093 **Kerry:** Like what you was saying earlier about not being
1094 able to accept your illness. (**Mark:** yeah.)
1095
1096 **I:** That's what I was thinking, how does that fit in?
1097
1098 **Kerry:** I totally, even now, I constantly over reach my
1099 capabilities. I take on too much. (**Kay:** yeah.) I take on
1100 other commitments, I've taken on a new course and doing
1101 voluntary work and it's like my mind can do it all but my
1102 body can't keep up. (**Mark:** yeah.) And you're...
1103
1104 **Kay:** But you've got to have goals haven't you, otherwise,
1105 like Frank will come home some days and say, "What have
1106 you done?" And I like my house to look nice and you think
1107 some days to even take the Hoover from under the stairs,
1108 (**Mark:** ehm.) you can't do it. And then another day, when
1109 you're feeling good, you sort of, you want to do the whole
1110 house from top to bottom. And then he comes home and
1111 says, "Well you've done too much today", but if you didn't
1112 do too much I think you'd give in – do you know what I
1113 mean? (**Mark:** I do.)
1114
1115 **I:** So to challenge yourself - but there has to be a balance.
1116

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1117 **Kerry:** Yeah, I don't know. I think it's maybe you know
1118 setting your limits a bit lower and setting the goals to be
1119 attainable rather than out of your reach, because I know the
1120 people that have got better have just focused on getting better
1121 in themselves, and their health rather than external things. (I:
1122 Right. **Mark:** Yeah.)
1123
1124 **I:** Yes cause I mean, going back to what I said a bit earlier
1125 about being high achievers and being busy and all the rest of
1126 it I mean there's something about having a lot of control as
1127 well [Mark and Kerry agree.] with that. Then CFS comes
1128 along, and takes control and you know, and it's like you have
1129 a relationship from what you are saying with your CFS or
1130 ME. But this thing has come and in some ways you know
1131 especially what you were saying Mark, it's robbed you of lots
1132 of things, [Mark agrees.] of lots of things, of your marriage,
1133 you know, of being with your son of all these things. And
1134 Kay, not being with your grandchildren the way you would
1135 want to be and your grandchildren [Kay agrees]. I was
1136 wondering about that, I mean have you ever thought of it in
1137 terms of a relationship? 'Cause it seems like when it is by the
1138 way you talk about ME, it is separate from yourself – is this
1139 making any sense?
1140

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- 1141 **Kerry:** I don't know, I think sometimes you can tend to
1142 think the ME takes over your life so much you tend to think,
1143 "Oh am I the ME?" do you know what I mean? (I: Right.) I
1144 said that to someone, "Am I the ME?" (Laughter). 'Cause
1145 it's so much part of my life, you know what I mean, it's
1146 constantly there - and I want to do something oh god you
1147 know you cant do it
1148
1149 **Kay:** Do you think it's frightening that it's constantly there
1150 sometimes?
1151
1152 **Kerry:** Erm, I mean it's not so bad as it used to be, but you
1153 tend to adapt better as you have it longer. But I think it is, it
1154 does, it can have a tendency to take over you and your
1155 personality, your identity even - because you know with the
1156 ME and as the symptoms are you get brain fog, fatigue...
1157
1158 **Mark:** That was the point I was going to say earlier about
1159 getting tired though, you know as I say physically tired.
1160 When you were saying about doing an OU course and all
1161 these sort of things it's - it's how mentally tiring things are
1162 and, you know, as you say the brain fogs and the headaches
1163 and all that kind of stuff that doesn't, you know it's not just,
1164 perhaps so commonly acknowledged. But that even makes,

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1165 you know, if just walking around that was tough and well you
1166 could just sit there and you know...

1167

1168 I: Yes – so there's the cognitive effect. (All agree.)

1169

1170 **Kerry:** I find the fatigue is the worst. I mean I could
1171 manage if it was just muscle pains, and not being able to walk
1172 around I've adapted to that – it's the fatigue that limits me
1173 from doing things. Mostly because I just get so exhausted I
1174 just have to lie down all the afternoon, and you know, you
1175 have to have regular rest whatever – but it's that – I think
1176 that's the main symptom for me anyway apart from anything
1177 else. (I: Yes.) 'Cause obviously the pain, pain is hard to
1178 cope with but you can take painkillers. Fatigue, you know,
1179 there's nothing that eases it.

1180

1181 **Mark:** When I'm feeling like that and I have a coffee it just
1182 makes me feel ill. You know, when I'm feeling okay and I
1183 have a coffee gives me a little boost. If I'm feeling bad a
1184 coffee is just gonna make me feel – you know, it just makes
1185 you feel worse. It's a strange thing it might make you more
1186 alert but it just makes you more aware of feeling rubbish in a
1187 way. (Kay: That's right). It's just I mean the point you are
1188 making (I) about the ehm, (2) the ehm [huffs] I've lost my
1189 train of thought (2).

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1190

1191 I: Well I'm trying to think about what point I made.

1192 [Everyone laughs.]

1193

1194 **Kerry:** It's a memory loss. (**Mark:** Oh deary me!)

1195

1196 **Kay:** That's how I am. They all think I'm daft at home – my

1197 daughter and my husband and they say, "Oh she's gone

1198 again."

1199

1200 I: I'm talking about having a relationship...

1201

1202 **Mark:** With the, oh yes. It's how hard you are on yourself

1203 and how, you know, I think I have accepted now that I've got

1204 the condition. I've finally got to a stage where you know I

1205 don't expect to get better, you know, I think that's important

1206 thing to come, you know – I hope to get better.

1207

1208 **Kay:** Yes come to terms with it.

1209

1210 **Mark:** Yes but it's that thing, you know, I don't want to

1211 wake up every day thinking, you know, today's the day I get

1212 better and then you know by ten o'clock...

1213

1214 **Kay:** You get the disappointment.

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1215

1216 **Mark:** Yes I've accepted that, and I've accepted that I may
1217 never play football again, and that you know, was hard. I've
1218 accepted, you know, I think that over a period of time you do
1219 adapt you know – giving things up straight away is hard.

1220

1221 **Kay:** You have to otherwise you'd crack wouldn't you?

1222

1223 **Mark:** Yes, but I still, you know, I'm still you know, I have
1224 a lot of things I enjoy in my life.

1225

1226 **Kay:** You try new things don't you?

1227

1228 **Mark:** Yes, but I'm saying but that's the point I'm finding
1229 new challenges, new things. (I: Yes.) You know, I'm
1230 writing a book. I got into, when I thought I was still well, I
1231 got into internet-based football writing. (I: Right.) That lead
1232 to sort of, quite a lot, you know I write quite a lot on the
1233 internet – quite a large following. (I: Fantastic.) People said
1234 just write a book – I'm writing a book... (Kay: That's
1235 fantastic.) So I've written nearly finished writing a book,
1236 ehm I've already got 500 pre-orders for it to sell.

1237

1238 **Kay:** You wouldn't have done that before though would
1239 you?

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1240

1241 **Mark:** See no I wouldn't of done that, and I think about that,
1242 and think that someone could say, "Wow", (2) but I would
1243 still rather be playing football than writing about it. But you
1244 make the best of it! But now I've set my, but now I'm
1245 thinking, "Oh alright", you know, I've now set myself under
1246 pressure because it's sort of time-sensitive. It needs to come
1247 out this summer, it's nearly finished, but then you start
1248 thinking, "Am I doing too much?" Then it's the whole thing
1249 of, well if I make a little bit of money out of it, will it just end
1250 up that I lose my benefits? (I: Okay.) And then I end up
1251 actually worse off. You know I have to borrow money off
1252 my parents to get by, because my housing benefit doesn't
1253 cover my rent or anywhere near. I mean I get incapacity
1254 benefit but that doesn't – and it's also the thing that people
1255 will then say, "Well if you are well enough to write a book!"
1256 But then I can – my day is completely my own [Kerry and
1257 Kay agree.] If I write for an hour then, you know, I can feel
1258 rubbish for 3 hours or feel rubbish for the entire day. I don't
1259 have to do anything, the hardest thing is...

1260

1261 **Kay:** The pressure's off you isn't it? (**Mark:** Yes, yes.)
1262 That's how I feel because I'm not at work I haven't got that
1263 ultimate pressure of saying you've got to get up dressed and
1264 get out the door for nine or whatever – my day was back to

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1265 front to everyone else's, but if I'd have had a normal job. But
1266 now I mean I always make sure I'm dressed for say ten
1267 o'clock, and I won't go to bed in the day – but I've got a
1268 recliner chair so it's that it's better for me to get in the chair.

1269

1270 **Mark:** I've got to that stage as well.

1271

1272 **Kay:** So I watch the telly or read if I can, I can't always
1273 concentrate but I make sure I will not let myself be in my
1274 dressing gown all day, you have to don't you?

1275

1276 **Mark:** That's, that's a big thing. [All agree.] I mean I set
1277 my alarm in the morning, and I used to sleep during the day
1278 when I felt rubbish, but then it affects my sleep at night. [All
1279 agree].

1280

1281 **Kay:** 'Cause I still have nights when...

1282

1283 **II:** It's all management isn't it.

1284

1285 **Kerry:** I just tend to lie down. I don't go to sleep I just lay
1286 down and rest [Mark and Kay agree] instead of sleeping.

1287

1288 **Kay:** That right it's like resting your body isn't it? [Mark
1289 and Kerry agree.] But I can still have, but not so bad now, at

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1290 one time I would be up two or three nights a week. Now it's
1291 once or perhaps two times a month, but I still make myself
1292 get up and get dressed in, you know. I get in the chair in the
1293 night, and watch the all-night telly, which is a blessing
1294 [laughter] that it's on. Do you know what I mean? 'Cause
1295 your mind won't go to sleep, and you're in so much pain and
1296 then you sit in the chair, but even then in the morning I won't
1297 go to bed – I make myself go and have a shower and get
1298 dressed. (I: Right.) Otherwise...

1299

1300 I: So you are keeping those - your own standards?

1301

1302 **Kay:** You've got to haven't you? Otherwise you become a, I
1303 don't mean a couch potato as such, but you know what I
1304 mean.

1305

1306 I: Yes, yeah I do know what you mean.

1307

1308 **Kay:** You would live every day in your dressing gown and
1309 never comb your hair (2). You've got low esteem anyway,
1310 you don't want to go any lower do you know what I mean –
1311 you've got to find a level that you won't go under.

1312

1313 I: So it seems as well...

1314

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- 1315 **II:** Sorry to interrupt (I) its half two now so it's just gone
1316 over an hour.
1317
- 1318 **I:** Alright thank you very much. Is everyone okay to carry
1319 on a little while longer? [All agree.] Say 15 minutes? [All
1320 agree.] Sorry I know that some of you have someone waiting
1321 [directed at Kerry]. I was thinking that the characteristics of
1322 people that have ME/CFS, I mean these things are
1323 generalised really and it doesn't count for everybody, but it
1324 seems like these qualities that you have you need them to
1325 manage the CFS. It's almost like you need to have some
1326 control in a way, over how you work your day-to-day life and
1327 how you manage your life.
1328
- 1329 **Mark:** Routine, routine is definitely important. (**Kay:** Yes
1330 definitely).
1331
- 1332 **Kerry:** I don't think you maybe have those qualities or
1333 maybe don't have those qualities developed to start with, I
1334 think maybe they develop as you progress with the ME.
1335 [Mark and Kay agree.]
1336
- 1337 **I:** Yes certainly it does sound like a process.
1338

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1339 **Kerry:** I certainly didn't have any self-control over my ME

1340 (laughter) as some will say. (Mark: No, no.)

1341

1342 **Kay:** So in the end you have to otherwise you...

1343

1344 **Kerry:** You do don't you? (Mark: Definitely.) It certainly

1345 developed with me anyway.

1346

1347 **Kay:** [Name of therapist] helped me plan my day, half hour,

1348 half hour, half hour – work half an hour, rest half an hour,

1349 work half an hour, and rest half an hour. You sort of ... you

1350 can't do that sort of every day all day - but it does help

1351 sometimes to say look well instead of working for an hour

1352 and being absolutely shattered, work for half an hour sit and

1353 perhaps have a coffee or sit and read the paper.

1354

1355 **Kerry:** I think it depends on the person because I'm very

1356 much a person of extremes I tend to go over what I can do...

1357

1358 **Kay:** Well I am but...

1359

1360 **Kerry:** And do a lot and I can't, I can't have a restricted plan

1361 or that model. I mean I did when I first got referred to the

1362 chronic fatigue clinic – you know the psychiatric nurse said

1363 to me, "well you do this and you pace yourself like this". I

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- 1364 did that, and to be honest it made me a lot more depressed
1365 than I was to start with... (I: Right.)
1366
1367 **Kay:** I can't do that all the time.
1368
1369 **Kerry:** It's so restrictive and I was thinking, "God is that
1370 what I'm doing each day? I'm doing the same thing each day
1371 am I going to increase it by 5 minutes – 'is that all my life has
1372 resorted to'" (Mark: Mmm.)
1373
1374 **Kay:** She just sort of taught me to sort of not do more than
1375 half an hour...
1376
1377 **Kerry:** I mean there is two sides to the coin but...
1378
1379 **Kay:** But you do, when you feel like well and want to
1380 Hoover for an hour you do – you know what I mean.
1381
1382 **Kerry:** Yes I can see that.
1383
1384 **II:** It's something I think, well I don't know what (I) will
1385 think of this, but the last group as well I think we were
1386 talking about everything was very individual. And I suppose
1387 like the whole thing about how therapeutic things that are

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1388 given almost as, you know, I suppose as a health professional
1389 you are given your package aren't you, like the GP...
1390
1391 **Mark:** Yeah (in agreement).
1392
1393 **Kerry:** Yeah. It's not gonna work for everyone is it?
1394
1395 **Mark:** It needs to be adapted to peoples' particular situation.
1396
1397 **II:** But yes you need to broach that with people, and get
1398 them to try some of it, but it's very individual, so what works
1399 for some people may not work for somebody else...
1400
1401 **Kerry:** Yeah, I think that's the same with any sort of
1402 therapy, or alternative therapy because people have said to
1403 me, "Oh this tablet's cured me, this homeopathy has helped
1404 me", and I don't know about anyone else but I've pursued
1405 every single... (**Mark:** Yeah. **Kay:** I have.)
1406
1407 **Mark:** Yeah I'm quite cynical about that 'cause it's
1408 something like, you know, you'll get like, "I've cured myself
1409 of ME by doing this!" (**Kerry:** Yeah.) You know, and you
1410 think you know well a, you might have been getting better
1411 anyway; b, that might have worked for you, you know it is an

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1412 individual thing. [Kay and Kerry agree.] You know I've
1413 tried lots of different things.
1414
1415 **Kerry:** Yeah, I've had about thirty or forty different
1416 therapies...
1417
1418 **Mark:** Yeah, a lot of people have. You know, you've got to,
1419 sort of, as I say, cause a lot of people do, it is cyclical, a lot of
1420 people do get better, a lot of people get better (2) then people
1421 say they're cured of it and they might get it in five years
1422 time! (Kay: Yeah that's right.) I know people who have had
1423 it, lost it and then it's come back...
1424
1425 **Kay:** It's like being in remission isn't it. (Mark: Yeah.)
1426
1427 **II:** Can I just ask, thinking about the different therapies, do
1428 you think - in terms of things that were helpful and things
1429 that weren't, going back to this idea about relationships, do
1430 you see any, when you reflect back on it now, was part of it
1431 about your relationship with somebody?
1432
1433 **Mark:** What as in the treatment?
1434

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1435 **II:** Yeah, because I know that when you were talking about
1436 seeing [name of therapist], it sounds like that was different to
1437 other relationships...

1438

1439 **Kerry:** I mean, yeah I found that particular Chronic Fatigue
1440 Clinic was err, I mean [name of therapist], I did find that very
1441 beneficial in terms of helping me to communicate. You
1442 know, and proving communication in confidence with talking
1443 about my illness, you know, that sort of thing. But I did find
1444 that it tended to go round and round. Erm, how to explain it?

1445

1446 **II:** Is that with [name of therapist]?

1447

1448 **Kerry:** Yeah. I did find that I didn't get any resolution
1449 sometimes to my problems. I know there obviously isn't a
1450 clear resolution always, but erm, I didn't find that, erm, I
1451 found it sometimes going round in circles, do you know what
1452 I mean? And that maybe something that was more solution-
1453 focused, you know, or goal-setting, that sort of thing would
1454 have been more beneficial.

1455

1456 **Kay:** Do you think there is a solution?

1457

1458 **Kerry:** No, no I don't mean a solution to the illness, I mean
1459 maybe you come with certain erm issues, to erm therapy.

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1460 And maybe having some goals would (2), you know, in terms
1461 of recovery, would have been more beneficial, you know, in
1462 addition to that, and maybe helping with self-esteem, 'cause I
1463 didn't really think that anyone really covered that. 'Cause I
1464 think that is quite a big issue with the illness. (Mark:
1465 Definitely.) Improving self-esteem and self confidence will
1466 help you, you know, whether you are still ill or you're
1467 starting to recover. Because it is one of the major things I
1468 think, you know, with the illness and part of getting better as
1469 well. (I: Right.)

1470

1471 **Mark:** It doesn't mean that you have had to have had sort of
1472 low self-esteem before hand. (**Kerry:** No.) I mean once you
1473 have got the illness your self-esteem does reduce, drop...
1474 (**Kerry:** Take a knock...) I think that is erm, I don't know if
1475 there is, if there are any group sessions? I mean I've found it
1476 quite helpful to sort of come in and chat about it. One thing
1477 is there's an Internet forum that you know I've kind of
1478 contributed to, and I pop on that every now and again. Erm,
1479 for sort of people in their twenties and thirties, and I think
1480 you know erm, that's been pretty helpful for me to discuss
1481 things with. You know it is nice to discuss it with people,
1482 and I don't know if there are any other groups? And I
1483 phoned up one ME group and, the (name of city and name of
1484 group), they've become some splinter faction from the one

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1485 ME group, cause you know all the ME groups were getting
1486 political and...

1487

1488 **Kay:** That's like, that's how the Fibromylgia Society got.

1489 **(Mark: Yeah.)** And I used to get a newsletter every month.

1490 **(Mark: Hmm.)** And then the National one wanted to take

1491 over the [name of city] one **(Mark: Right, laughs)**, but I've

1492 never gone - actually to it.

1493

1494 **Mark:** No, but it's nice if you...

1495

1496 **Kay:** But the newsletter was quite helpful to receive. But I

1497 had, I had this idea in my head, I said to you, it was like there

1498 would be all old people rattling round the table XXX

1499 [laughs], you know what I mean? The chap that I spoke to,

1500 the secretary, his wife has ME, erm, fibromylgia, and he sort

1501 of is the secretary of the group. And he was on for ages and

1502 ages, and it was just like, I came off there and I was that

1503 depressed [Kerry and Mark laugh], when I was talking to

1504 him, I thought [all laugh] if I felt like that then, what am I

1505 going to be like if I go to the group. So I never went!

1506

1507 **Kerry:** Yeah, some of them can be really negative, I went to

1508 one **(Kay: Yeah)**, all that they basically did was sit there and

1509 wallow in it!

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1510

1511 **Mark:** Oh yeah, I had thought about that, yeah!

1512

1513 **Kay:** And I didn't want to do that...

1514

1515 **Kerry:** It was like it was their major hobby, part of their

1516 occupation in life was to sit there moaning about it!

1517

1518 **I:** But I guess it's...

1519

1520 **Kay:** It might help them, I don't know!

1521

1522 **Mark:** It's nice to moan as well. (I: Yeah [all laugh].) If it's

1523 the only time you get when everybody else takes you

1524 seriously then...

1525

1526 **I:** Well I was thinking that perhaps what might help them is

1527 that others can relate to it, so it's a common experience.

1528 (Mark: Yeah.)

1529

1530 **Kerry:** Yes it is good to share common experiences, but I

1531 think, my mum went there actually to do a talk, she's a

1532 therapist, an holistic therapist - she did a talk on ME and

1533 therapies. And she said none of them were interested in

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1534 really, you know, approaching anything or trying anything

1535 new.

1536

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

1538 early diagnosis...

1539

1540 **Kerry:** I think some of them - they'd had it quite a long time

1541 and they were prepared to sort of, just live with it.

1542

1543 **Mark:** Or maybe they'd tried everything...

1544

1545 **Kerry:** Mmmm, I don't know but...

1546

1547 I: Okay, I understand what you are saying...

1548

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

1550

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

1552 well...

1553

1554 **Kerry:** Oh yeah, well there's desperation isn't there, of

1555 getting better. [All agree.] I remember seeing therapists

1556 charging very extortionate prices. I've tried this new thing, I

1557 don't know if anyone's heard of it, reverse therapy. There's

1558 been quite a lot of, well there's been a bit of press about it

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1559 but, I actually tried that after I got, you know, I stopped
1560 seeing [name of therapist], and err, 'cause a number of the
1561 people said that it cured them. (Mark: Right.) That it's this
1562 new cure for ME. (Mark: Mmm.) Ermm, and it has helped a
1563 friend of mine, it's helped her quite a lot, she was really
1564 severe, but it didn't help me unfortunately and it was sort of
1565 eighty pounds a session. (Mark: Yeah). So it's quite, it's
1566 quite, you know, I'd built up my hopes to think "this was the
1567 cure, this was the one thing that's gonna do it", and it didn't.

1568

1569 I: Do you think that therapy helps you and the ME, or does it
1570 help you, and the ME stays the same? (Kerry: Erm.). Do
1571 you know what I mean?

1572

1573 Mark: I think that the better, the better you...

1574

1575 Kerry: Well it builds up hope. I think it gives you hope,
1576 'cause there is that feeling of, you know, of desperation, that
1577 "Oh I'm going to get better. Or am I ever going to get
1578 better?"

1579

1580 Mark: I think that if things help you, then the ME can be
1581 helped as a result of that.

1582

1583 I: A knock-on effect?

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1584

1585 **Mark:** A knock-on. But you know, the better I feel in
1586 myself mentally, I might still feel rubbish physically, but but
1587 you don't you don't think "Oh I'm just gonna, I'm gonna..."
1588 You can still perhaps motivate yourself. And I think, I know
1589 that if I went out, I can have days where I feel fine, and I
1590 know from the past, you know I could go out and do
1591 something I didn't think I could do, but then you pay the
1592 price.

1593

1594 **Kay:** Yeah, yeah, that's right

1595

1596 **Mark:** You know, erm, I think if you feel good and you
1597 know, if you push yourself too far but you don't go too far,
1598 you know, then, you can kind of manage it and you have your
1599 ups and downs...

1600

1601 **Kay:** I think you do have to push yourself a bit though.

1602 **(Mark: Yeah.)** Otherwise you become (2) well...

1603

1604 **Mark:** I think, I think I'd find like graded, erm graded? (I:
1605 Graded exercise?) Yeah graded exercise, stuff like that I'd
1606 find really hard to do cause days where I have my son, you
1607 know, he's a three year old, you know, he's not going to

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1608 understand the concept of ME. [All laugh.] He's like
1609 "Daddy do this now." So...
1610
1611 **Kerry:** And sometimes pacing regimes can cut out all the
1612 fun out of your life, and sort of days, the days where you sort
1613 of, maybe want to do something that is a bit mad,
1614 spontaneous...
1615
1616 **II:** Yeah, I was gonna say, it takes away the spontaneity if
1617 everything's planned. (**Mark:** Yeah.)
1618
1619 **Kerry:** And I found that life's so bloody miserable at times,
1620 that I didn't really want to...
1621
1622 **Mark:** Well it's nice to have a routine but it's nice to be able
1623 to scrap the routine, and have some flexibility.
1624
1625 **I:** So it sounds like it needs to be realistic.
1626
1627 **Mark:** Yeah. And you don't want your hopes built up and
1628 anything as well. So, with any kind of treatment, if you are
1629 going through feeling, I mean when I was diagnosed the guy,
1630 you know, was getting me a list of things to take for the first
1631 month, and it came to nine hundred pounds. Now, after, in
1632 the end I did about six months, you know - without paying

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1633 for everything on that - but it was probably about three
1634 hundred pounds per month. And then when I realised, I felt
1635 better in myself, (I: Right.) as I was on a complete detox diet,
1636 and err, usually I felt better, and then you get cravings for
1637 things back, and then when I realised it wasn't going to cure
1638 me. Then it's very hard to, you know, to be on a seaweed
1639 diet or something, you know, if you know it is not going to
1640 make you better in the long-term. And you can do it if you
1641 think it's going to. Then after that you come down because
1642 you're not better, do you know what I mean? So you've got
1643 to kind of be open-minded but not have your hopes raised,
1644 you know.

1645

1646 **Kerry:** Yeah, it's about being realistic about what the effects
1647 are going to be.

1648

1649 **I:** So it's about balance again? [Mark and Kerry agree.]

1650

1651 **Kay:** You've got to be quite strong minded I think. I used to
1652 go home from seeing [name of therapist] and be absolutely
1653 exhausted. And I'd only sat talking to her, but it was just
1654 like, relief's not quite the word, of being able to explain to
1655 someone that I felt understood. Because you can talk 'til
1656 you're blue in the face to somebody else and they'll just look
1657 at you as if you're a zombie. Do you know what I mean?

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1658

1659 **II:** Yes. I was just wondering really, you've all said a lot
1660 about different relationships in your life, but if you reflect on
1661 different relationships in your life - generally as a whole,
1662 including professional and personal ones, do you see some
1663 relationships mirrored in others?

1664

1665 **Kerry:** Yeah I think, as I was saying earlier the empathy,
1666 you know, and the understanding.

1667

1668 **II:** Did you find some of that in personal relationships as
1669 well?

1670

1671 **Kerry:** I think, certainly with my parents, I mean after a
1672 couple of years, I think at first, there always was, you know,
1673 disbelief. (**Mark:** Mmm.) But I think as they see you with
1674 the illness, and as you progress with the illness, I think they
1675 can, sort of, get that understanding and sort of empathy...

1676

1677 **Kay:** It's hard for them isn't it?

1678

1679 **Kerry:** It is hard, it is hard.

1680

1681 **Kay:** I think if I was your mum, I would be desperate to help
1682 you.

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1683

1684 **Kerry:** Yeah, especially as she's a therapist. [All agree.]

1685 She was very much about "Oh I am going to cure you", sort

1686 of thing, and that was her project...

1687

1688 **Kay:** I am lucky 'cause Frank is marvellous. He does the

1689 ironing and things I can't do. And...

1690

1691 **I:** Yes it sounds like Frank really understands your

1692 experience.

1693

1694 **Kay:** Yeah, yeah. He'll say something some days, and you

1695 think (2) "But, I thought you understood." But they can't

1696 understand hundred per cent.

1697

1698 **Mark:** Not a hundred per cent, no.

1699

1700 **Kay:** But he does his best. And your parents obviously do,

1701 'cause it's good for you to have that err, unit that does help.

1702 I'm lucky that my daughter's good and my son-in-law's

1703 good. You know, and my grandchildren know that (1) I can't

1704 do what his other nanna does. (**Mark:** Yeah.) I mean they

1705 bike from...

1706

1707 **Kerry:** It's having a support system...

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1708

1709 **Kay:** from [name of town] to [name of city] on a tandem. [I
1710 and Mark laugh.] You know, I couldn't do that when I was
1711 well. [All laugh].

1712

1713 **I:** What do you think Mark to II's point about relationships,
1714 in that can you see any relationships in your life mirrored in
1715 what you had therapeutically?

1716

1717 **Mark:** Ermm, erm, my mum was pretty good about, you
1718 know, she'll get things out the paper, and I believe that my
1719 mum believes me. [I: Right.] I kind of half believe that my
1720 dad does but he's seventy-five, he doesn't really understand,
1721 you know what I mean, but you know he's got a lot better
1722 now, I think he takes me seriously, for years he thought I was
1723 just a lazy git really. Ermm...

1724

1725 **Kay:** That's hard isn't it?

1726

1727 **Mark:** Yeah. And my friends, I haven't got any friends that
1728 would even talk to me about it, or ask me about it - no friend
1729 has asked me how I am...

1730

1731 **Kay:** No, erm, no, people don't. (**Mark:** They ask me...)

1732 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
1735 of a bit of a silence. And I've made friends, you know,
1736 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
1743 understanding...

1744

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

1746

1747 **Kay:** I'm lucky, see I don't have that. (**Mark:** Mmmm). But
1748 then I don't have a big circle of friends, since we left the pub,
1749 my life's pretty much at home, and, with my daughter and
1750 Frank...

1751

1752 **Kerry:** Yeah, I think you do find that you have fewer
1753 friends. But, mainly better... (**Kay:** Yes better friends.)
1754 Better quality friends, and quality relationships.

1755

1756 **Kay:** But people that I was sort of, when I was in the pub
1757 and we had a night out, you know, a night off, and we'd go

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1758 out with, all of them have gone (2). But things like my son-
1759 in-law's mum and dad we're, we're all like a close extended
1760 family now. And, but, as, I've one friend who's seventy-five,
1761 so she keeps up with me and I keep up with her. [Mark
1762 laughs with Kay.] It's silly really but you do find your circle
1763 of friends shrinks.

1764

1765 **Mark:** I think if you've got just purely social friends, they'll,
1766 they'll go. (Kay: Yeah they go.) [Kerry agrees]. Well they
1767 are not like proper friends. All my friends are dotted all over,
1768 I've not got many friends here, cause I'm from XXX, and
1769 then from university I've got friends there, but you know
1770 everyone's, but you know, that's the great thing of, you
1771 know, without the internet and email I think I'd go mad,
1772 'cause I can keep in touch with everybody.

1773

1774 **Kay:** Still have a few social friends as such, but not the
1775 social friends that say "Ooh I'll meet you next week and
1776 we'll go to so and so". You can't be that spontaneous. You
1777 have to sort of wait 'til the day and then you ring up and say,
1778 "I'm sorry we're not coming", because Frank wouldn't go
1779 without me. You know, and in the end people stop inviting
1780 you. (I: Right). And that's quite hard. So in the end you
1781 don't do what you did do...

1782

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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

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1807 town, or go out on my own or anything! And I drove here

1808 today on my own.

1809

1810 I: Good, so things have really moved on for you.

1811

1812 **Kay:** Yeah, you just make your life different!

1813

1814 **Mark:** Yeah. I'm in a better place than when I first came

1815 here. Perhaps I would have been anyway, 'cause you rebuild

1816 your life anyway...

1817

1818 **Kay:** I feel better than I did in my head a year ago. Not in

1819 my body but in my head. And that helps you to carry on

1820 doesn't it? (**Mark:** Yeah.) I, you can see the wood for the

1821 trees sort of thing.

1822

1823 I: Certainly. Kerry did you want to add anything?

1824

1825 **Kerry:** I don't think so. Like you say, I think it has been

1826 valuable - definitely, you know, to speak about your

1827 experiences.

1828

1829 I: Right, I'm glad you have all got something out of it, I

1830 certainly have.

1831

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1832 **Kay:** Are you doing this for the university? Is it like a
1833 university course that you're doing?

1834

1835 **I:** Yes I'm at Leicester University.

1836

1837 **Mark:** Sorry. Do you have friends, do you, have you got
1838 any ME groups on the Internet that you're (2) [directed at
1839 Kerry]

1840

1841 **Kerry:** Not ME groups, I've got friends that I email.

1842

1843 **Mark:** Right, I can give you my email address, I mean I
1844 haven't got the website, but I'm now excluding - or partially
1845 excluded, 'cause it's only for people in their twenties. [All
1846 laugh.] So I've kind of been booted out really. [More
1847 laughter.] But there is a really good group of people on there.

1848

1849 **Kerry:** Oh good that would be great!

1850

1851 **Mark:** So and there's somebody from round your way. Erm,
1852 I can't remember where it is but there's a girl that lives very
1853 close to where you are.

1854

1855 **Kerry:** Yeah that would be really good

1856

**Focus Group 3: 18th March 2005 at 2.00pm.
Three Participants that had been Discharged from CFS Service**

1857 **Mark:** Have you got a piece of paper?

1858

1859 **I:** Yeah sure. So is everyone feeling okay? [All participants

1860 say yes.]

1861

1862 **Mark:** Is there any other websites or advice things you know

1863 of for ME?

1864

1865 **I:** This has come up in other groups, and to be honest with

1866 you I don't know, but if I do find out I will post the

1867 information to all participants.

1868

1869 **Mark:** Right thanks!

<p>Group ends. All participants thank each other and say goodbye - then leave the room.</p>

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.
16

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

19

20 Helen: Well when I started at the end of January, I thought
21 by sort of like, well now we are at the beginning of April, I'd
22 thought yeah, I'd be well into it. And we'd be thinking about
23 returning to work in the summer. But I've had one
24 appointment, and that was just on what Chronic Fatigue is.
25 (I: Right okay.) So, I'd been on the Internet and everything, I
26 was well read on it.

27

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

30

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

32

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

35

36 I: What are your expectations of therapy?

37

38 Helen: Erm, well I've filled in my charts for two weeks
39 about what my activities are - which the next time I see
40 [name of therapist], she'll go through with me, to sort of
41 establish a baseline. And then hopefully, it's advice sort of on

42 like erm, maintaining the energy I have got, and how to
43 actually progress, 'cause I seem to have plateaued out a bit
44 [laughs]. I'd been doing all right, and I seem to have
45 plateaued out. So hopefully, with [name of therapist]'s
46 advice, that we're gonna be able to step it up, and I'm going
47 to keep getting her to step my energy up. (I: Right.) Erm,
48 and looking at going back to work. And erm, there's the
49 cognitive behavioural therapy as well - whether she does it or
50 somebody else, I'm not really sure - about looking where I'm
51 at and erm, and then hopefully in building me to go back to
52 work, 'cause it's the same Trust, hopefully, it's going to be
53 looking at, you know, it's going to overlap with me going
54 back to work. Well that's what I'm hoping anyhow!
55 [laughs]. So I've still got [name of therapist] while I'm still
56 trying to go back to work. And I'll be going back to work on
57 therapeutic hours. Which is part of the Trust policy to go
58 back to work on therapeutic hours.

59

60 I: What are therapeutic hours?

61

62 **Helen:** Well therapeutic hours are, I can work up to - I still
63 stay on the sick, and still be covered with a sick note, and I'm
64 still - well I don't get paid now as I've been off for over a
65 year. But I'll go back to work, and I can work up to sixteen
66 hours a week. (I: Right.) And I'm supernumerary, and it's

67 just to get back orientated into the job and the office and the
68 people and what's going on. And, if during the day I feel
69 tired or feel ill I can just go home 'cause I'm supernumerary.
70 And it depends on my Occupational Health Doctor how long
71 I do that for, on average it's about a month, but I think he's
72 thinking about two months for me. Em, and then, when I'm
73 happy, then, well everybody's happy, then I go back to work,
74 and resume my job. (I: Right.) And then all the time that
75 I've had at work I'll have back as time owing.

76

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

78

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

85

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

88

89 **Helen:** [clears throat] Erm (1) yes and no. Yes in that they
90 followed the sick procedure, as in, erm (1) I've had regular
91 sick reviews, the first six months, which is with my initial

92 Line Manager, the G Grade - erm, and now it's with, erm, the
93 Team Leader, my Union Rep and Personnel. And they're
94 regular and they just say, "Yes, how are you doing?" But
95 from the point of why I was sick in the first place, which was
96 caused by, or in my belief, stress at work - I don't feel that's
97 been addressed, and I'm still quite bothered about that! (I:
98 Yes.) That, you know, work has contributed, in my belief, to
99 my illness. And nobody's actually sat down and said, "Well
100 alright then - we can't change what's happened. But, you
101 know, we will support you or take on board what's happened
102 or (1)." 'Cause I could say about going back to work but just
103 be in exactly the same boat [laughs]. So, I think that that's
104 my only thing from work that I, I've tried to address, but it's
105 been half-heartedly, "Yes okay, we're dealing with it." But
106 nothing's concretely been said, you know, like this is
107 happening or we will look at this when you get back to work.
108 So that's one of the things I'm going to try and get in-built
109 when I do go back. But, and also because of the nature of the
110 illness, you know I don't want to be negative and sort of like
111 say, if I go and relapse or whatever - but obviously it's in the
112 back of my mind. I want to stay positive, you know but it's
113 in the back of my mind that if I go back into a totally stressful
114 situation that I'd left, that I'm gonna sort of like end back in
115 this spiral, or whatever again.

116

117 I: That sounds like a difficult situation to manage. So there
118 is a part of you that wants to go back to work but you are
119 aware of the risks that are attached to that.
120
121 Helen: Yeah and it's how much work is going to take on
122 board. I had a sick review last week and I did say, "You
123 know, I'm concerned about the staff's attitudes to me when I
124 do go back." 'Cause obviously, this sort of illness there's a
125 lot of controversy around it anyhow [laughs] and it depends
126 who you talk to, whether you're a medic or psychiatrist, what
127 you believe or, do you know what I mean? And people at
128 work - they have seen me, I mean I have been in touch and
129 been in work (XXX), and tried to keep in touch with them,
130 and they're just like, "Oh you're looking well." But inside
131 they can't see, you know, all the pains and the aches, the pins
132 and needles, all the other bits and pieces that are going on in
133 me. And, I think they kind of think - they don't understand
134 where I'm coming from, they don't understand why I'm still
135 off, and (1), you know, they don't - so one of the things I
136 have asked when I go back to work is that there is some sort
137 of awareness about my, my illness. 'Cause am I going back
138 cured, am I going back just in relapse, you know? And I
139 don't want them to think, "Oh yeah, C's back, you know,
140 she's back in her job here you are," boom, "here's your
141 caseload." You know, off you go, and six months later I'm,

142 you know, I'm ill again. So (2) - but work has said that we
143 can do some sort of awareness, but it's, it's me as well, can -
144 have I got the guts to turn round and say, "Well no I can't do
145 it 'cause I'm not well today." Do you know what I mean? I
146 don't want to let people down, and (2). I don't know,
147 perhaps I'm being, sort of overly-bothered about it. It will
148 probably not be that bad, I'm probably thinking of the worst
149 scenario when I go back. But, it's still - I feel that I need to
150 protect myself because (1) despite the stress last year, and me
151 speaking up at work that I was stressed, nobody did anything
152 to help me. So I feel I have to put this like, protection around
153 me when I go back. (I: Yeah.) Because I've got to protect
154 my health, and you know, not put my family through what
155 they've gone through as well.

156

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

159

160 **Helen:** There was a lot of stress, it was, it was a very unusual
161 situation in that my line manager, my G Grade, was on the
162 sick, and the Team Leader was on the sick [laughs]. So I had
163 another G Grade that was sort of overseeing, and he was
164 really really stressed. He was just a general pig to all of us,
165 but I got the brunt of it because I'm the F Grade. Erm, and,
166 there was an unusual circumstance with a particular case that

167 (1) I wouldn't normally be in, so, erm, it was very stressful.
168 So it was an unusual situation, and I know I'm not going to
169 be going back to that exact situation, but it does bother me
170 that (2), you know, things can happen. But, you know, I did
171 say, "I'm stressed" when I had supervision, and everything
172 was written down, but nothing practical was ever done. (I:
173 Right.) And that's what I wanted to happen. I don't know
174 what, perhaps I'm just imagining that (1), that they should be
175 doing things that was impossible. I don't know, but I just
176 didn't feel that I was looked, you know, looked after. I
177 became very cynical about my job, and (1), 'cause my job's
178 been my career - well now it's - it's just a job. When I go
179 back it's just a job. My whole view of my job's changed.
180 Because I feel very cynical about what's happened to me by
181 the Trust I work for.

182

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

185

186 Helen: No I think, erm, in the last twelve months I've totally
187 re-evaluated my life, and my priorities have changed. I've
188 been very much, ambitious, well, driven and want to get on
189 [laughs]. And suddenly, with being ill, it's like well hang on
190 a minute, is this happening, you know, I believe this is all
191 happening for a reason and I'm just trying to work out what

192 the reason is. My priorities have changed, in that I've
193 become totally more family-orientated, and (1) - my family
194 was never neglected, you know, we always did things. It's,
195 it's just this, I've just changed, I've just sort of like changed
196 the, you know, that my family are more important, and I will
197 go back to nursing, but in a few years time I want out of
198 nursing now. I'm so "Grrrrr," about what's happened
199 [laughs].

200

201 I: So what do you foresee in your future?

202

203 **Helen:** Ermmmmmm, (2) short-term and not quite sure
204 which way I'm going to go - long-term, erm, I want to sort of
205 work more, sort of abroad. I've want, wanted to work
206 abroad. I think I'd move abroad if it wasn't for my daughter
207 because I'm not with her dad - so (2) both my husband and I
208 would like to go and do some - like work in Africa or sort of
209 voluntary work or something abroad. But that's sort of like
210 long-term. How I get from where I am now to that, where I
211 do some voluntary work, erm - cause when I go back to work
212 I'm only going back part-time. So, you know, that's where I
213 sort of - it's still going to be something to do with the caring
214 profession, but not for an NHS Trust. [Laughs.]

215

216 I: Right, because you feel let down by them? (Helen: Mmm
217 yes exactly.) So you've spoken about possibly moving
218 abroad to do some voluntary work with your husband, have
219 you developed the plan since the CFS started?

220

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

228

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

231

232 Helen: No, not at all, not at all. It was, it was just like living,
233 I suppose, from day-to-day, and thinking, "Yeah one day I
234 will do it, and one day I will think about it." I mean, not just
235 that, just sort of anything, any hobbies or interests or
236 whatever. You know, it's like; when I've got time I'll do
237 that, or decorate the house even or anything. Do you know
238 what I mean, it's like "I will get round to that, I will get
239 round to it", but never did, because it was just every day sort
240 of like every day, just living. You know, in the fast lane, you

241 know, just surviving, make sure the bills are paid, you go to
242 work and my daughter's at school - you know, just all the
243 basic stuff, it's just hard work.

244

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

250

251 **Helen:** Absolutely, absolutely. You know I've always, you
252 know I have my down days, you know, I could just sit and
253 cry some days and think, "What the Hell's happening?" But
254 I suppose because I'm quite an open and spiritual person, I, I
255 try and see the bigger picture, and I suppose that's really been
256 since the beginning of December that I've sort of like, got to
257 grips with being ill and this is where I'm at, and I've sort of
258 seen the bigger picture. I want what's happened in the last
259 twelve months to, to mean something, do you know what I
260 mean, I don't want it to just be - go back to how it was, and
261 I've not learnt anything from it or not made any changes
262 because of it. 'Cause I do believe - 'cause when I look over
263 my life, I mean, my stress, I do get stressed, and different
264 things that have happened in my life, and I feel like it has all
265 built up to like, this moment. In that, I've perhaps had signs

266 of things happening before, and you just like shrug it away
267 and you just sort of like carry on. And I think in the end my
268 body's just turned round and said, "Hang up a minute! You
269 know, you can't keep going on like you have been." And (2)
270 another thing is, is that I'm a very impatient person. Well
271 with CFS you can't, just like forget about it, or "Today I'm
272 going to be well", cause you can't do with it. And I've had to
273 really learn to like sit with it, which has been one of the
274 hardest things I've had to do. Because I just wanna like, well
275 if I want to do something I'll go and do it! You know, like
276 before, whereas now have to think, "Well I can't, or or, you
277 know, I physically can't do something, and erm, I can't sort
278 of pretend I've not got it today". You know it's always there!
279 And, it's, I think that's been one of the biggest things is
280 patience I think, I've got to just sit and wait or whatever
281 gonna happen with my treatment or, you know, that's been a
282 big thing for me.

283

284 I: Would you say that you're a more patient person now?
285 [Helen shakes head and laughs]: No. [Both laugh.] Okay so
286 you've learnt to cope with impatient.

287

288 Helen: Well yeah, I think I'm learning, but I think I've, I
289 need to sort of like, erm, transfer the patience bit that I'm
290 learning from CFS to other areas of my life. I can still be

291 inpatient about, you know, I don't know, waiting - I'm ready
292 to go out and waiting for my husband or whatever, and I can
293 be like [sucks in air through teeth], you know. But, you
294 know I have to transfer that skill that I've got to sit with the
295 illness to everyday things. And that's I suppose the point that
296 I'm at, at the moment, where I just sort of like need to chill a
297 bit. [Laughs.]

298

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

310

311 Helen: Well (2) there's one other major thing, I mean, my
312 marriage and everything, my relationship with my daughter
313 and everything is fantastic. I've been married for five years,
314 and he is fourteen years younger than me. The only issue that
315 was going on in our marriage at the time was that - I've just

316 turned forty (2) and, err, in January, and James was twenty-
317 six. And I've got a daughter from a previous relationship,
318 and we were talking about starting a family. And that was a
319 big issue, erm, I suppose about the time I become ill but we'd
320 been trying sort of, for about five or six months. And, erm,
321 because I was really stressed, that, I felt that it was stress that
322 was contributing to the fact as well that I wasn't getting
323 pregnant. So course each month it was very disappointing-
324 and as much as I was trying not to be disappointed every
325 month [laughs], it was just like; well I'd think, "Ooh the
326 biological clock's ticking." And it's a big decision about us
327 having a baby, cause we were not bothered either way, but
328 (2) it was just one of those things, "Am I going to regret it
329 when I'm a few years older - James has not got a child." So
330 that was going on at the same time. And, erm (2), and I see,
331 sort of like the ME, sort of a bit of like, "Ooh it's stopped my
332 plans, 'cause I'm like forty now and I'm not pregnant, and
333 it's like ERRRRH." You know, so I see that as a bit of a
334 hiccup for James and I as well, and, I mean we have been
335 tested, there's no reason why we can't. But, erm, and I've
336 also got, erm, erm, low hypothyroidism, which got diagnosed
337 whilst I've been off. So it's like all that, like "Oh, we're not
338 going to have a baby then." And I, I'm not devastated but
339 (2), it's just one of those issues that we felt, if I was twenty-
340 six we'd have a lot of years to sort of like plan and think

341 about when it was ready - but because my biological clock
342 was ticking away, I felt like [gasp] I've got to make a
343 decision, and what happens if I make the wrong decision? So,
344 sort of like (2), sort of like six months before I, well I became
345 ill in the March, so about five or six months before that we
346 had made a decision sort of like, yeah we'll try, and if it's
347 meant to be it's meant to be! But erm, I think you know,
348 with having like the ME, it's like, "Ooh is this stopping me."
349 It's made me resent it a bit as well. But, if it's not meant to be
350 then it's not going to happen, and I just have to try and be
351 philosophical about it, and not think too much about it. Even
352 though I've got these like three baby nieces and nephews
353 around, four baby nieces and nephews around at the moment,
354 it's like [takes an exaggerated intake of air then laughs]. But
355 that's the only thing that was actually going on at the time -
356 was work and then this major decision, and deciding what we
357 was going to do. But there was nothing, nothing else major
358 going on that I'd got any worries about.

359

360 I: Right. So there were two pressured things going on at the
361 time (Helen: Yes.) Even though you say, "What will be will
362 be", well I guess if you're trying you're trying. (Helen:
363 That's right yes.) You said something earlier about your
364 spirituality, and seeing the bigger picture, what does the
365 picture look like?

366
367 **Helen:** Erm, (2), I think it's just been, I mean spirituality has
368 only been sort of like something that I've addressed, I
369 suppose in the last four years and that's been 'cause I was
370 influenced by somebody that has came to work in the office.
371 And, erm, four of us in the office, we all became spiritual and
372 got into our angels, and I've been reading up, and sort of like
373 become, sort of like quite a spiritual person. I just read it, it's
374 something that's private to me, and I don't go to spiritualist
375 church or anything like that. It was just really to see, sort of
376 erm, about what life is about - what the meaning of life is.
377 And I suppose one of the things is like, what is my role in
378 life? And am I fulfilling it? Am I fulfilling my destiny as it
379 were, and err, and I've done a lot of reading and I've got
380 these archetype like cards that I've got as well. I'm trying to
381 work out my personality; I mean I'm into all that [laughs].
382 Erm, and, I just seem to be drawn to that, it just seemed
383 important for me to find out what life was about for me. And
384 I did have a big thing about, oh years ago, about four or five
385 years ago, about dying - which I've got no fear about that
386 now at all because I believe in like reincarnation and
387 everything. So, it has been a major major thing to me, but it
388 is a lot of comfort - but it's not like you're church bible
389 bashing, sort of dogmatic things from the church, it's just
390 spiritual that gives me a lot of comfort.

391

392 I: Sure, and what did you find out about your role?

393

394 **Helen:** I'm erm, I'm a rescuer- which is something that - I

395 suppose that's why I'm in nursing. But, I think it's more,

396 it's, all of it still came down to me, sort of like, the healing

397 role, the sort of like caring role. You know, all that - well I

398 say "nursy nursing"- but not necessarily in a nursing way. I

399 mean, more sort of like the voluntary work I suppose now.

400 And erm, but it was, it was all around sort of like working

401 with people. (I: Yeah.) But it's just that I want to save the

402 world! That's because I am too much of a rescuer [laughs].

403 You know, I want to be able to, you know, like with my job, I

404 want to be able to go in and solve - cause I go into families - I

405 want to solve all their problems and obviously I can't do that.

406

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

408

409 **Helen:** I just beat myself up over it. I just say to myself that,

410 you know, "Oh well I've failed as a Community Nurse, or as

411 a human being, or", (1), "whatever." You know, but I can't,

412 that's one of the things that I've realised. I had a big

413 conversation, ooh I few weeks ago now, with my dad of all

414 people. And he was, because my dad was all very ambitious,

415 that's where I get it all from. And even my dad says, "Ooh,

416 when you've got your twenty years pension, you can leave
417 and go and work in Tesco or somewhere," [laughing], which
418 for my dad to say, is, and had this big conversation (2) about
419 drive and about ambition. And he was saying, "You want to
420 go in and solve everybody's problems and you just can't."
421 And he was saying, you know, "Just go in and do what you
422 can, maintain them but, you know, stop beating yourself up if
423 you can't wave your magic wand, 'cause you haven't got
424 one".

425

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

427

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

437

438 I: So you found the conversation quite liberating?

439

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

448

449 **I:** Well parental relationships are important.

450

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

452

453 **I:** How would you describe your mother?

454

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

465 know, I think she's always been brought up to think it's

466 selfish to think of yourself first.

467

468 I: Do you think that too?

469

470 **Helen:** Yeah, I have done, yeah. I think in recent years I've

471 tried to address it. The reason why I've addressed a lot of

472 things is because erm, I suppose it's four or five years ago I

473 started a three-year training to do erm, person-centred

474 counselling. So I'm a qualified counsellor. So, I suppose

475 I've looked at myself quite a lot then, and that's where a lot

476 of my self-awareness came from, so, that's how come I know

477 myself.

478

479 I: And the CFS sounds like something that has - well it has

480 stopped some of your plans - but it sounds like it has also

481 made you think more about yourself. (**Helen:** Yes.) I know

482 that there are cognitive symptoms of CFS, but in a sense

483 when your body is not able to do things you have got time to

484 reflect on your life. (**Helen:** Yes.) I was interested in what

485 you were saying about your parents, in that your dad wanted

486 you to achieve success and your mum wanted to almost live

487 through you - that sounds like a lot of pressure.

488

489 **Helen:** Yes very much so. Dad always wanted the best for
490 us. I wanted to be a nanny when I was sixteen, now I was
491 going to live abroad and be a nanny, see I've always wanted
492 to work abroad! It wasn't good enough for my dad, and he
493 wanted me to be a school teacher, "You can do better!" He
494 persuaded me to stay on at sixth form, and I, I think that is
495 the first real memory I've got of, my dad, you know, sort of
496 like, you know looking back, cause obviously I look back a
497 lot thinking about how much my dad influenced me. And
498 that was, at the time it didn't seem much, but when I look
499 back now, that is a big sort of thing in my life. That I never
500 went down the path that I originally wanted to go on, because
501 my dad knew something I'd had a bad experience, he didn't
502 want me to go abroad because he couldn't keep me safe
503 [laughs]. So, you know, and at the time I was just like,
504 "Yeah, well all right, whatever." And I went into sixth form,
505 dropped two 'A' Levels, I couldn't cope with sixth form - I
506 hated it! You know, it was just a time for messing around in
507 the Common Room, and [laughs] discovering boys [laughs]
508 and all that sort of stuff. I didn't want all of that (1) pressure.
509 I didn't want to go to university or anything. But erm, you
510 know, and I managed, you know, and I eventually got into
511 nursing, but err, you know, at the time I just thought, "Okay
512 fine," accepted it but now I can be quite, (1) quite bitter about
513 it if I let myself. You know, dad didn't let me do what I

514 wanted to do! But, you know, it's all water under the bridge
515 now. But, there was a lot of pressure. I don't know how
516 much, my dad did put pressure on us, but I think I also
517 increased that pressure. (I: Right.) It was like, you know,
518 how much did my dad really want me to do, or how much did
519 I think my dad wanted me to do? So I think I put that extra
520 pressure on myself as well, I can't blame it all on my dad
521 [laughs].

522

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

527

528 **Helen:** Erm (2), some of me, I think, was, I don't know what
529 to call it! I suppose the reward, the pay-off for actually
530 helping somebody, or self-worth that I could help somebody,
531 and you know, you saw their life improve and they thank you
532 or whatever. I think it was some of that, you know, my
533 personal self-worth for my own self-esteem as well that I'd
534 helped somebody. That made me feel good as well, as well
535 as them feeling good, it's not always just about the self is it.
536 That it was very much I think, you know, I got a pat on the
537 back for it, or whatever, and I needed that! I needed - I
538 suppose 'cause my self-esteem was probably low I needed

539 almost to feed on me helping somebody else to build up my
540 own self-esteem.

541

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

543

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

555

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

558

559 **Helen:** I think that's how - I've just always been like that.
560 Always, I was never in trouble at school - I just always
561 wanted to please, and you know, be good and get praised, and
562 you know, get recognised for it - the same at home. I wasn't
563 always a little saint at home - I did have a bit of a gob on me

564 [both laugh]. Because I would try and stand up for my rights.
565 Or what I believed or my opinions, but because my dad was
566 really strong it was just totally shot down in flames, I was -
567 so I backed down and I still do that now. Confrontation I
568 back down straight away, 'cause everybody else is right and
569 I'm wrong - because that was like the relationship I had with
570 my dad.

571

572 I: Yes, and you are aware of repeating patterns. When you
573 were talking about your father, I don't know if this sounds a
574 bit odd - but I pictured you as a little girl getting squashed in
575 a way.

576

577 **Helen:** Yes very much so, very much so yes.

578

579 I: Yes it certainly comes across that you are reflective, and
580 you sound like you have pieced things together from your
581 past, because I guess you are who you are and also the kind
582 of job that you do. How do you think you coped with that
583 pressure to please as a child? I guess what I mean is how has
584 this affected your current relationships?

585

586 **Helen:** I think I want more from people. I think I've lived a
587 lot of my life through what I think other people want me to
588 do, particularly my parents. Erm (2), I wouldn't say - in

589 some ways I'm independent, erm, but in a lot of ways I
590 would say I rely on other people for that, for that feedback.
591 I'm not sort of a person who can be on my own. It's like in
592 relationships with men, if a relationship's been failing, I
593 wouldn't split with that relationship until someone else was
594 there to replace it. It was like, I couldn't be on my own, and I
595 couldn't survive on my own. But, I suppose yeah, I am
596 influenced a lot by people around me.

597

598 I: Right, and let's think of it in terms of CFS. If you imagine
599 CFS to be person, how would you describe your relationship
600 with that person?

601

602 **Helen:** Erm, (4) it's really hard to sort of like say.

603

604 I: Yes it is. Well what would CFS look like if you had to
605 describe it, what would it look like?

606

607 **Helen:** Erm, (6), I don't know really, erm, (3), I don't know,
608 somebody quite strong, quite dominant. (I: Yes.) Yeah sort
609 of powerful, strong.

610

611 I: Okay, powerful and strong (2) and in what way does that
612 affect you?

613

614 **Helen:** Well it's controlling my life at the moment. I can't
615 get away from it - I can't (3). You know, 'cause even if I try
616 and stand up to it, it's almost like, it's like the confrontation
617 thing, you know. If I was trying to stand up for myself, like
618 you say, I could be squashed, and I suppose that's what I see.
619 Because I've tried lots of things, I've read up on things, I've
620 had alternative therapies, you know, I've really tried to
621 research it and help myself. And, (2) and then at the end of
622 the day I just seem to get squashed by the illness again. I sort
623 of like seem to take a step forward and then about three back!
624 That's how it feels, you know, and I get quite sort of
625 frustrated with that. (I: Yes.) But then there's still
626 something in me that hasn't gone, "All right, I give up to it,
627 I'm just gonna lie down," [laughs]. And just sort of like, go
628 in a corner somewhere. But I still sort of like come out
629 fighting. 'Cause I suppose that's that drive thing that I've got
630 to overcome it - you know, I've got to make this count or,
631 you know, make the changes or whatever. And I just think
632 that it's a process of how I feel now about it is obviously
633 different to how I felt six months ago. So it's been a process
634 of how things have happened and how my view has changed
635 towards my illness. You know, you have to go through
636 processes don't you.
637

638 I: Yeah, sure. Do you think that process is what everybody
639 would go through who had ME? Or do you think there are
640 things about you as a person - your personality if you like,
641 that would influence the process that you would go through?
642
643 Helen: Yeah I think so. I think it does depend on the
644 individual. You know, this is just my opinion. (I: Yeah,
645 sure.) Cause I've read about people that have had it for years
646 and years, and I couldn't imagine being ill that long. And
647 erm, and I just think that because I have this personality- that
648 I see a problem and I have to solve it, that, and I have got that
649 awareness and that drive, I don't know - it might even hinder
650 me, you know. This could be because I've hindered myself,
651 because I've been so wrapped up - particularly the first six
652 months about - "Why am I ill? Why me?" And all that!
653 [Laughs.] You know I've got to find out! That in the end
654 I've just had to let that go. I suppose like, what I was saying,
655 it's part of the process. But (2) erm, I do think that because I
656 got this sort of awareness and 'cause of my spirituality and
657 seeing the bigger picture, that I could imagine that people
658 who haven't got that, and, sort of the support I've had at
659 home with my husband, that, you know, you could just say,
660 "No, you're better just staying in all week." I could just see
661 people, you know, de-conditioning and sort of not having no
662 social contact and becoming more down and depressed. I can

663 see, that, you know, people getting like that and the illness
664 prolonging.

665

666 I: So in a sense then, what you are saying is that if you don't
667 fight it - it will beat you - you will succumb to it and become
668 depressed?

669

670 **Helen:** Erm (3). I don't necessarily think that fighting it has
671 been right for me as well. 'Cause sometimes, 'cause I have
672 been fighting it - then I have a bad day - I just think I'm
673 failing. So [laughs], so then I beat myself up about it. I think
674 I probably go to the extreme [laughs]. You know, by really
675 fighting it, and I've got to like - you know, I think I've had to
676 lay off it a little bit and sort of be a bit more realistic about
677 (2) seeing it as the enemy I suppose. More like accepting it,
678 this is where I'm at and, I've got it and for whatever reason -
679 I mean it's been important that I find out why, because I
680 don't want it to happen again. And I feel if you find out why
681 something has happened then you won't let it happen again.
682 But I can't, you can't always - I've got an idea of what's
683 contributed to it, but, and I suppose that I just have to be
684 happy with that - an educated guess I suppose.

685

686 I: This is the thing with CFS though isn't it, there is no
687 agreed cause, and there is no agreed treatment. The

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 -

713 whether it's more about me just having a hang-up about
714 having a mental illness or a psychological problem I don't
715 know. But I just feel it seems more orientated towards that if
716 you see what I mean.

717

718 I: Yes I do understand and I think that is an issue for lots of
719 people. In terms of that, would it better if it was in a more
720 neutral building? Or is it because the service comes under
721 the umbrella of psychiatry in [name of city].

722

723 **Helen:** Yeah I think it is, and also, I suppose, I mean I've not
724 spoke to my people at work, but obviously we work for the
725 same - we work in the [name of speciality], and that is still
726 part of our service but in mental health. They're not
727 understanding my illness and they see that I'm going to the
728 [name of Mental Health Ward]. [Sucks in breath through
729 teeth then laughs.] It's like, "Ooh what are they thinking!"
730 Or is this just me in my head or or whatever. I just feel that it
731 ought to be a neutral sort of thing and sort of like, yeah like I
732 say, there probably is a bit of both, but it just seems that it is
733 mainly aimed at sort of more psychological then (3).

734

735 I: Yes it seems that there is a psychological versus physical
736 health debate regarding CFS that has somewhat plagued

737 peoples' experiences and preoccupied researchers and
738 professionals for a long time.
739
740 **Helen:** Yeah I think 'cause just in the press and everything -
741 it's, it's just controversial and everything as well. You know,
742 obviously it's improved from like the eighties when it was
743 called "Yuppie Flu" and whatever. Because it is an illness
744 that can't be proved under a microscope or whatever, then it's
745 got to be in your head or you're just imagining it. And (2)
746 you know obviously things have changed since like the
747 eighties, but there are still a lot of negative people out there
748 that don't understand it or see it as it is just all in your head -
749 and you've brought it on yourself. And - and it's probably
750 things that I've asked myself as well [laughs]. You know
751 like have I brought this on myself because I erm (2) you
752 know, I'm psychologically not balancing or whatever you
753 know. So it's just something that has gone through my head
754 for myself as well.
755
756 **I:** I guess it's very difficult to understand an illness when
757 there is no mainstream agreement about the illness. And as
758 you said, it may depend on whom you talk to as to what
759 opinion they will have about it. So in that sense it is bound to
760 impact on you isn't it?
761

762 **Helen:** And also cause like I have a real thing about what
763 people think of me. And, I like to blend in, I don't like to be
764 centre of attention [laughs]. I like to just blend in and just be
765 like part of like the team or whatever. But because I've got
766 this illness and there is this controversy around it, and also
767 working with people that don't understand it, and I'm going
768 to the [name of Mental Health Ward], then it's bothering me
769 what I think they're thinking of me. Which is, you know, am
770 I being, I know all about labelling and being stigmatised, I
771 work with [name of client group she works with]. So (2) and
772 I know how they get labelled, and I'm thinking, "Well are
773 people (1)", - people probably aren't even thinking about it!
774 But you know what it's like! You just think, "Well are
775 people (1) or." And I suppose that - that bothers me 'cause
776 obviously when I go back to work I need to explain to them
777 what's going on and they need to sort of understand my
778 illness. And, you know, if I've got this mental illness stigma
779 attached to it 'cause they see me go to the [name of mental
780 health ward] it's (2) you know. It bothers me but that says
781 more about me than them. (3) You know.
782
783 **I:** What do you think would help you cope with your
784 concerns about what people think of you?
785

786 **Helen:** Erm (3). Well from work, I mean I'm - we are going
787 to go in or whether we get [name of therapist] to go in and
788 talk to the staff, 'cause it's the same Trust. Or whether I go
789 in and do some sort of awareness, erm, a lot of it will be done
790 through my Occupational Health Doctor as well, 'cause he's
791 obviously going to be putting into to place what I'm going to
792 do when I go back to work and the guidelines. So hopefully
793 that's going to help. But the main thing is about; erm, what I
794 say me, how I view it - or how I think other people are
795 viewing me. And that's something I need to address for
796 myself. So that in the future if anything comes up it doesn't
797 really matter what anybody else thinks. I'd like to be like
798 that, and don't care if they think I've got mental health
799 problems, I know what it is, do you know what I mean? But
800 I also feel that I have to justify myself - and, you know,
801 where I'm at; what I'm doing; why am I like I am, and you
802 know, and that's something I would like to change about
803 myself. To be more like "I don't care what you think!"

804

805 **I:** That sounds like you want to change something that is
806 very intrinsic to you, as you said yourself, you have tried to
807 please others since you were a little girl.

808

809 **Helen:** I've been like aware for quite a lot of years about
810 things that make up my personality, like this drive and

811 everything- I've been aware of it, I've been aware of it. And
812 things happen and like I get angry about something, and I just
813 put it down to my personality, I go "Well that's me!" But I
814 suppose recently I've been thinking, "Okay that's all right
815 that it's me, but I could also challenge that." And I've
816 always just accepted that that is my personality - but I really
817 believe now that I can challenge things in personality and
818 make some changes. (I: Right okay.) Which, you know, in
819 rather than just accepting that's me because I'm a mardy cow
820 or I get really angry or whatever [laughs]. But, you know, I
821 can say well, you know, have I got any grounds to it? And
822 actually challenge it, and perhaps try and rationalise it a bit
823 more than it being irrational. And that's what I'd like to do
824 about a lot of things. And that's when I think about having
825 the ME, is that I've been aware of all these things but I've not
826 done anything about it - and now is the time that I have to
827 address them. How - I'm not quite sure but (2) it will
828 happen, [laughs] bits of it will happen. You know, when I
829 say I want this to count, that's part of it as well, it's changing
830 the parts of my personality that I can change or challenge or
831 (2). You know, just because I feel it or it's a habit or
832 whatever it doesn't necessarily mean that it is right for me so
833 (2) that's what I'm hoping to do [laughs].
834

835 I: Right. So if we go back to your experiences of the CFS
836 Service, you have had one appointment to date, which was in
837 January?

838

839 **Helen:** I mean [name of therapist]'s really nice, I hit it off
840 with her straight away. I felt very comfortable with her. And
841 (2) and I felt straight away, you know, that I could talk to her
842 and just really be open with her. I did feel a bit - when she
843 gave me some information on Trudy Chandler? Or
844 somebody or other - some information book that she'd
845 photocopied for me about the approach that they use, and
846 about like filling in your timetable for like two weeks - and
847 then it's going to be like put under the microscope - and I feel
848 a bit [gasps] defensive over that! But I'm sure that - 'cause
849 [name of therapist] is so nice, you know, I think she'll (2)
850 she'll gently [laughs] she'll gently say, "Well perhaps."
851 'Cause I've said to her, you know, if you criticise me I'm
852 going to be [sucks in air suddenly] - so she knows! I think
853 she'll be fine.

854

855 I: Okay so you sound like you have an optimistic view of
856 your future therapeutic relationship. And the important thing
857 is that she is listening and she is nice and you can be honest
858 with her.

859

860 **Helen:** Yes definitely. She seemed to know where I was
861 going from when I was saying things - you know, obviously
862 from her experience with other people, 'cause I haven't really
863 met anyone who has got ME or really talked to them so (1).
864 Yeah because like GPs, and you know doctors have been a
865 bit vague about things - to actually talk to somebody that was
866 finally like, "Yeah, I know where you are coming from!"
867 That was a great relief. You know like, "I'm not going mad.
868 There are other people out there like me!" Do you know
869 what I mean? (I: Sure.) Within - being - having ME I'm
870 normal do you know what I mean?

871

872 **I:** Yes I do. I feel in some ways we have managed to get
873 much more in-depth about personal reflections because it is
874 just you and I talking. But in other ways it's a shame that
875 other people didn't come to the discussion, because for many
876 of them it was the first time they had met other people with
877 CFS. I've been struck by the impact that has had on people.
878 It has seemed very important to share experiences with each
879 other and feel accepted. I feel sad that you have not had that
880 opportunity. Again, in terms of the CFS service, if I was to
881 say to you what would an awful therapeutic relationship
882 consist of, what comes to mind?

883

884 **Helen:** I suppose it would depend on their personality, you
885 know, their experience - obviously [name of therapist] had
886 got experience of it and understood - she'd heard it, you
887 know, all before, you know. I suppose obviously people have
888 to start at the beginning, so if it had been somebody new that
889 obviously didn't understand, and I think it's the people skills
890 as well! You know, in how we sat, I think from just meeting
891 her straight away, you know, it, it, there was just something
892 there that - and I don't know if it was because she was a
893 woman. I mean I don't know how I would have been if it
894 was a bloke. Erm, I met the erm [name of Consultant], and
895 he just scared me to death! It was just like [inhales sharply
896 and loudly to indicate horror]. I, I met him as erm, (1) in his
897 private capacity, because I'm making a claim with [name of
898 Insurance Company] for my income protection, and he was
899 the one that did my assessment. And I found out he was over
900 the Chronic Fatigue Unit. So but when I met him he was just
901 like "Wooh", he was just like, I suppose 'cause, 'cause he
902 was about seven foot tall [laughs]. And I don't name 'cause
903 he was like a Consultant Psychiatrist as well, 'cause I've got
904 a thing about, erm (2), like status as well. And although like
905 I talk to people, Consultant Psychiatrists in my job, I can talk
906 to them as an equal, but as soon as I walked into like him, it
907 was just like "Who," 'cause I suppose it was about myself.

908 And I did find him quite intimidating really. I was in tears
909 and glad to leave [laughs]. Whereas like (3)

910

911 I: Because of his physical appearance and status?

912

913 **Helen:** Just some of the things of how - his actual manner.

914 And comments (XXX) and things that he actually said, it
915 was, you know, there wasn't a lot of eye contact, and, do you
916 know what I mean? It was the (1) - so I suppose I put a bit of
917 a barrier up. Well with [name of therapist] straight away, I
918 just, and I suppose 'cause like she's petite and she's very
919 gently spoken, and err it all sort of affects doesn't it?

920

921 I: So interpersonal skills and appearance are important?

922

923 **Helen:** He was quite opinionated as well. Some of his
924 comments that he made were quite, "Oh okay." Whereas
925 [name of therapist] is sort of listening, and although she gave
926 advice, it was sort of done more in a non-confrontational sort
927 of, non, sort of like, judgmental way. Whereas he was like -
928 he wasn't critical against me - he was critical against GPs and
929 it was just how he said things, and I was just like, "Whoops!
930 I wouldn't want to get on the wrong side of you." [Laughs.]
931 I'm sure he's a very clever man and whatever but [laughs].

932

933 I: Okay. I'm just aware of the time; we have been talking
934 for an hour.

935

936 Helen: Is that an hour! It's just flown by [laughs].

937

938 I: Is there anything that you can think of [name of assistant
939 researcher] that we have not covered?

940

941 II: There was one thing that I would be interested in
942 exploring what you thought. It was something you said a
943 while ago, you said that you have a lot of self-awareness of
944 how your qualities have influenced the type of career you
945 have. I wondered about how you felt about seeing someone
946 therapeutically given that you are a trained Counsellor
947 yourself - sort of sitting on the other side.

948

949 Helen: Yeah, it is really really strange being – 'cause like I
950 say working for the same Trust as well I know it's [name of
951 speciality]. But being a patient it is really really (2) it's really
952 different, it's just - I don't know, 'cause I don't want to be the
953 patient [laughs]. I don't want to be the one that (2) obviously
954 I want rescuing but obviously I don't want to be in that
955 position where I need to be rescued. Do you know what I
956 mean? (I: Mmm.) And to have like all this like the tables
957 turned - is really sort of like quite unnerving. I feel quite

958 insecure about it because (2) it's easier to talk about
959 somebody else's problems than putting yourself under the
960 microscope and sorting yourself out. Erm, because when you
961 are doing it in a professional capacity you go home at the end
962 of the day, you're away from it. I go home and I take it with
963 me still and it's, it's, you know, you don't switch off from it.
964 It is really strange, I can't really put it into words but it has
965 been really really strange. Particularly like talking to [name
966 of consultant psychiatrist], it was just, I'm so used to talking
967 to psychiatrists - you know, I do it most weeks in my job and
968 I have all my information there and suddenly because it was
969 about me - I couldn't - it's that confrontational thing again.
970 In my professional capacity I will stand up and I will XXX to
971 a psychiatrist and say that they need this, this and this.
972 Whereas when he turned round and said something to me I'm
973 like, "Yeah okay." [Laughs.] Which is really (3) you know
974 it's like a power difference I suppose. I feel more equal when
975 I'm on professional terms, but as a patient I felt very much,
976 sort of, you know quite low and they're the professional to be
977 looked up too, like I suppose I did with my dad.
978
979 I: Yes mmm. (2) I was thinking along the same lines. When
980 you think about how you felt let down in your job, well you
981 strike me as a person who would go all out to help another
982 person...

983

984 **Helen:** Absolutely yeah, I will stand up for them and I'd
985 have all my reasoning and I wouldn't back down. But myself
986 - I just back down. You know, I can't stick up for myself -
987 which is a bit weird.

988

989 **I:** But also it didn't sound like anyone did that in return - it
990 didn't sound like anyone stuck up for you.

991

992 **Helen:** No not all. Nobody no - at work nobody did, it was
993 just I don't know (2). It was like, "Yes Helen you are in a
994 stressful situation, okay, but we're not going to do anything
995 to help you." They knew I was stressed they knew what was
996 going on but nothing was actually done at that particular time
997 to help me. Which I think there's a lot goes on, that goes on
998 a lot our job. And also a lot of the people I work with - a lot
999 of them wouldn't admit that they were stressed anyhow -
1000 'cause they see it as a weakness, and the fact that I did was
1001 like, "Oh I don't care if I'm weaker than those, I'm stressed!"

1002

1003 **I:** So that takes a lot of guts to say that, especially when you
1004 knew that others might judge you.

1005

1006 **Helen:** Well I was really at the point where I knew
1007 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.

1031

1032 I: Right so the boundaries got blurred and things spilt.
1033 (Helen: Yes.) Okay, is there anything else you would like to
1034 say that you feel is important?

1035

1036 Helen: Well when - sort of like looking at services, we have
1037 just like talked about the actual Chronic Fatigue Unit. But if
1038 you take it a bit further back, was erm, problems with my GP.

1039 Erm, I mean like [name of therapist] was saying that hope to

1040 educate the GPs a bit more. But I have to change my GP

1041 within the practice - because of the attitude of the first GP

1042 was obviously "It's all in your head", and you know (2),

1043 "you're stressed from work, go back to work and if you're

1044 still stressed you're in the wrong job!" And it was like, he

1045 wouldn't even do blood tests or anything for three months

1046 [laughs]. So erm (2) and it was, and then I saw the erm,

1047 Occupational Health Doctor, and it was like, "Well, you're

1048 depressed." 'Cause I've had post-natal depression, "You're

1049 depressed." And it was only cause I changed my GP within

1050 the practice who had experienced Chronic Fatigue patients

1051 before, and then had referred people to the Unit, that she like

1052 said, "Yeah well I think something's going on here." And

1053 after six months I said, "Well you know what's my

1054 diagnosis?" She said, "Do you think you've got ME?" And I

1055 said, "Well yeah I'm convinced that I have," and she said,

1056 "Well there's your diagnosis." So I felt a bit cheated, I

1057 almost wanted them to do loads and loads of blood tests and
1058 say, "No its not it's something else, and here's a tablet and
1059 you're going to be better!" But it didn't, and I felt that first
1060 six months it was just a battle just getting recognised through
1061 the GP and Occupational Health Doctor. Erm, I mean the
1062 Occupational Health Doctor was from Psychiatry anyhow, so
1063 it was all (2) that approach. So, I think the initial service
1064 before you actually get to the Chronic Fatigue Unit is just a
1065 bit (3) you know (2) is not necessarily good. And I was
1066 fortunate that I did find a GP. In lots of ways I have been
1067 lucky compared to a lot of people I should imagine. But I
1068 ended up seeing a GP that, after three or four months that
1069 knew about Chronic Fatigue and believed me! And that I
1070 worked within the service so I got prioritised for the Chronic
1071 Fatigue Unit.

1072

1073 I: Yes it does seem like a lottery in regard to peoples'
1074 experiences with GPs concerning diagnosis and treatment. I
1075 hadn't asked you too much about your experiences with your
1076 GP as a lot of the other participants have spoken about their
1077 experiences and wanted to explore other themes in more
1078 depth with you. So in a way your experience is not unusual.
1079 I think it must be very difficult when you're in a job where
1080 other people are not behaving the way you feel you would
1081 behave in their position - and they go to the medical

1082 profession for support and get disbelieved and dismissed.
1083 But again you stood up for yourself and changed your GP.
1084
1085 **Helen:** Well in the end my Occupational Health Doctor
1086 knew it was, 'cause he kept saying that I was depressed, and I
1087 was adamant that I was not going to be labelled as depressed
1088 'cause I knew that it was something more than that. But he
1089 then in the end wrote to my GP and said, you know that I was
1090 really experienced in physical, you know illnesses. And you
1091 know, could they take that on board and support me. As that
1092 letter was going I changed over GPs in the practice - 'cause at
1093 our Practice you just go and see whichever GP you want. So
1094 I just went and saw a different GP, and just sort of said that I
1095 hadn't been happy with the previous GP, and that I wanted to
1096 be taken seriously. And for ten minutes she just sat there and
1097 listened to me, and I felt well this is good, because she's
1098 actually listening to me. And even though initially she didn't
1099 do anything - it was another three months before she put the
1100 referral in - I did feel that at least I was listened to and wasn't
1101 just fobbed off. You know, with, "It's all in your head," or,
1102 "Go and give up your job," or, "You can't deal with stress,"
1103 or whatever. It was, it was just again a whole different
1104 approach.
1105

1106 I: Yes it seems that you have had some fairly dismissive
1107 comments made to you. I know that [name of therapist] is
1108 planning to do a talk to GPs and let's hope that increases
1109 awareness of Chronic Fatigue. (Helen: Yes it's much
1110 needed.) So you said that the last time you saw [name of
1111 therapist] she gave you some activity forms to complete.
1112 How is that going?

1113

1114 Helen: [laughs] Well in my job I am always throwing out
1115 charts saying, "Fill these in."

1116

1117 I: So what's that like?

1118

1119 Helen: It's like I'm never going to ask them to do it again!
1120 [Laughs with researchers].

1121

1122 I: What impact has this experience had on your career as a
1123 nurse?

1124

1125 Helen: I think it has changed - well first of all I said earlier
1126 about it how it has changed how I look at my job - I mean my
1127 job was my be all and end all. Now it's a job I will go and do
1128 and come home. But erm, and try not to be the rescuer the
1129 same (2) that I've always done and I suppose accept my
1130 limitations a little bit more - I can't go in and (2) you know,

1131 wave this magic wand that we would all love to have and
1132 make everything better. I think I'm just going to have to take
1133 on board, you know, that I have been this patient in the last
1134 twelve months and gone through so I think it will make me
1135 think about what service I'm giving. Like you were saying,
1136 about like the therapeutic relationship - like I've got with
1137 [name of therapist] is good. But I suppose it's going to make
1138 me a bit more like - although I was aware because of the
1139 counselling - it's probably made me a little bit more aware
1140 when I am dealing with my clients and their families.
1141 Perhaps I am going to be, you know, a bit more open, you
1142 know, and try and create more of a therapeutic relationships.
1143 Rather than going in and saying "Here's your forms," and
1144 [laughs] you know, perhaps change my approach a little.
1145

1146 I: That sounds really good - although I guess it can be
1147 difficult to do that as a time-pressured Community Nurse
1148 with a big caseload. But it seems that from your training and
1149 experience you really know the importance of being listened
1150 to and understood and accepted.

1151

1152 **Helen:** Yeah. And I thought about when I go back to work –
1153 'cause like I was friends with everybody in the office. And I
1154 think I'm going to have to take a back step from all the
1155 political stuff going on in the office and just, you know, just

1156 stick to what I'm doing, do you know what I mean? Don't
1157 get involved with everybody else's lives [laughs] and what
1158 problems they've got going on in their work or whatever!
1159 It's, you know, I, 'cause I try and rescue the staff as well, you
1160 know, if they are having a stressful time - particularly junior
1161 staff, I'm like, "Well I'll do that for you and (2)." You know
1162 I've got to just, you know, be a bit different when I go back
1163 to work. And not be this rescuer who has got the magic
1164 wand! [Laughs.] That's going to be able to put everything
1165 right, 'cause I can't do it, I'm not that wonderful person.
1166 [Laughs.] But that's being more realistic, I don't mean I
1167 can't be wonderful. (I: Yes.) You know it's just unrealistic
1168 - I can't be that magical person that - because nobody can be!
1169 And I think I've got to perhaps learn my expectations a little
1170 bit - for my sanity I think! [Laughs.]

1171

1172 I: Well I guess it's about keeping yourself safe. (Helen:
1173 Yes.) And that is another boundary to be aware of I suppose.
1174 As you said earlier, one of the factors of becoming ill was
1175 when the boundaries blurred. (Helen: Yes.) But now you
1176 are aware of that - but I guess these things are easier said than
1177 done!

1178

1179 **Helen:** That's right! And I think, you know, if I go back to
1180 work and I bet in another six months it's just going to be the

1181 same. I'm going to be like, you know at [name of team
1182 member]'s beck and call and everything. But you know, I've
1183 really, you know, I've really got to sort of like hold myself
1184 back this time. I've really got to (2) you know, make the
1185 changes, not say I will and leave it, I've really got to make
1186 the changes this time. Because I don't want to go through the
1187 last twelve months again. You know I don't want to sort of
1188 have ME for years and years and whatever. I will just be -
1189 keep sane!

1190

1191 I: And take care of yourself.

1192

1193 **Helen:** Well yeah. 'Cause the impact that it has had on the
1194 family and things that we can and can't do you know, I don't
1195 want them to, you know, to keep putting my family through
1196 that. You know, you have to have a quality of life
1197 somewhere [laughs]. Not just in front of the telly with the
1198 chocolate [laughs].

1199

1200 I: Although that can be quite good too! [Both laugh.]

1201

1202 **Helen:** Not every day though!

1203

1204 I: No. Well I think we have come to the end of our
1205 discussion. Do you feel okay?

1206

1207 **Helen:** Yes I'm fine. I feel like I have just gone on and on.

1208 [Laughs.]

1209

1210 **I:** I'm glad that you have been able to be so open - I've

1211 found it very valuable. Thank you for coming. (**Helen:**

1212 Thank you.)