**Participant 7 Interview**

**EX-FRAIL CKD Trial**

AN: This is Dr. Andrew Nixon Clinical Research Fellow in Renal Medicine conducting an interview for the EX-FRAIL CKD trial IRS I.D. 244772 on *[date deleted]* with participant ID 7. Right [00:00:25] again thank you for taking part in this interview, [00:00:28] umm I think just as a starter for ten it would be helpful just to ask how you've found study?

PT: [00:00:40] I found it difficult in the beginning and once we talked about altering one or two things, I found it very helpful. [00:00:52] it took time to get into it. It doesn't, It's not something that is a quick fix overnight but as I got into it maybe after about four or five weeks I started to feel quite a bit of benefit and certainly where my legs were concerned so it was good doing the exercises [00:01:15] as you know I have a lot of problems with me joints and one or two of the exercises I've found quite difficult. But some of them I found quite enjoyable and also because of enjoyment I seem to find that it worked better.

AN: Mm hmm mm, [00:01:38] so why do you think it took a little bit of time?

PT: because I’ve never exercised for years.

AN: [00:01:43] Right.

PT: Never exercised for years due to the fact that riddling arthritis, kidney problems and psychiatric problems as well. There has been a number of things and I think it was like everything else, initially it felt very regimental that this is what I have to do. But once I got that out of my head and realized that it wasn't that I had a choice, but after speaking to you and saying right well instead of doing tens drop that one down to five see how you go with that, in some cases that was the exact thing that I needed and that gave me a bit of get up and go, it didn't seem, it didn’t seem too strenuous.

AN: [00:02:41] Mm hmm. So given that prior to involvement in this study you hadn't really done much physical activity…

PT: none

AN: what, what, what made you want to take part in the study?

PT: [00:02:56] well I look at this way; If the doctor offers you to go on a study that may or may not help you, you have a choice and the thing about it is at my age I'm sick of being ill.

AN: Mm hmm.

PT: and anything even if it’s only five per cent improvement in my life and my well-being then I felt that you know it was my obligation to me and also hopefully this will help maybe you with other people.

AN: ummm [00:03:37] yeah we hope so, hope so

PT: well that to me is [00:03:40] you know umm when you keep saying thank you for coming, I appreciate that [00:03:48] but the thing about it is that if I hadn’t wanted to do this study or even this interview I would have said I don't want to do it. You know I could have come for the initial interview may be tried one or two exercises when I got home and thought no this is not for me but to be quite honest with you that would have been foolish on my part because anything that will help is, is an improvement.

AN: yeah, [00:04:23] so it was the prospect of hopefully you having some improvement in your health and well-being?

PT: yes, without a doubt.

AN: ok, [00:04:36] good. [00:04:38] so how did you, have you got any comments on how you were approached to be involved in the study and the information you received?

PT: [00:04:47] well it was it was just something that I think it was through Dr XX and yourself emm meeting people that you feel you’ve got a trust for and to be quite honest with you, that's a big issue I have with hospitals erm due to the fact to what I've been through. Once I’ve found somebody who I could really connect with which I have done with Dr XX and then yourself, I really felt a real feeling that you're not judgmental and you were there to help and encourage and give advice. And I think that that was really the the thing that really drove me to want to do it.

AN: [00:05:50] so regardless of the information you get, [00:05:53] had it been somebody that you hadn't felt that way with do you think?

PT: I wouldn't have done it. I wouldn’t have done it, no no. I am very careful with doctors, though I used to teach up here, I fortunately I didn't come into contact with any doctors, erm but since I started a number of years ago now, I can't think of how many years but it must have been seven years that I've been with Dr XX, I really have got a distrust for male doctors and it doesn't matter whether they're white, Asian, black [00:06:39] it doesn't bother me. I just want to be treated normally and I think everybody does.

AN: hmm

PT: [00:06:45] I will give the respect back to the people that give me respect and that's what I find coming to this research facility. [00:06:54] Everybody is very kind and whether they talk about me behind me back it doesn’t matter because I am not there. It’s when people… you know what I am saying?

AN: hmm

PT: If people want to know about me I've always said come and ask me, [00:07:17] don't make assumptions, don't make a parody of something you don't understand and this really goes the same with this study, I didn’t understand it, I didn't know what I was letting myself in for but I've always been a bit of a risk taker especially like I’ve said with somebody that I felt very comfortable with.

AN: [00:07:42] I'm really pleased that that's how you felt and I'm pleased to hear that you felt you've been or at least I hope you felt that you can be treated with respect throughout the study.

PT: Absolutely [00:07:53] absolutely this is this is as good as you get for hospitals, yourself but also everybody else. You can have a bit of fun, yes it's serious, anything to do with health is serious but you get too regimental that you know I'm a doctor you've got to do this, see I’ve had that and that doesn’t work for me, in fact that works in the opposite for me, I fight back at that.

AN: Yeah

PT: Because I'm I'm a strong woman who knows my own mind and I just want to do things that I feel is better for me.

AN: Yeah, [00:08:41] so the information that you received, [00:08:46] do you feel like that gave you, I know it was a while ago now, [00:08:50] did you feel at the time that gave you enough information to understand and make…

PT: [00:08:55] Yes without a shadow of a doubt, I mean thing about it is in our first thing the interview emm obviously there was a physiotherapist and there was also another gentleman and between you, you didn't make it complicated, where unfortunately with some doctors but also with the general public, people can make something that so simple that they can make it sound so complicated. That's one thing I didn't get here, I understood everything. If I had a question you was willing to answer and willing to listen. And to me that that was the big thing when we started on these exercises, I felt uncomfortable, but you listened and you said well we'll try it this way and we’ll work up. But you didn't say well next week you’ve got to do so many or so many.

AN: umm hmm.

PT: what you did was say we would like if you feel up to it to do up to three sessions a week and you know once we dropped them down from ten to five…

AN: Yes

PT: initially, then that was fine. But as I felt more confident in myself that’s when when we talked on the phone that I decided to up it up a little bit even though you were a little bit nervous because you were you know you were concerned about me. You weren't concerned about this. You were concerned about me as a person and that to me is important.

AN: yeah

PT: that every person is treated the way that they feel is going to help them not because this study says you've got to do ten of this, ten of this, ten of that, ten of that. If you can contrive it to make it acceptable for the feeling and I'm talking about the physical feeling and also the mental well-being…

AN: ummm

PT: I think that’s, that's where it works Andy.

AN: [00:11:10] so without wanting to… from what I understand from what you're saying is that is it the fact that it was adapted to you to you as an individual that made…

PT: yes, yes, yes.

AN: and [00:11:30] the flexibility in…

PT: yes, yes that's a good word is that the flexibility of being able to do though it was written down that you want to do three and 10, three of that, that's fine, but initially if I'm going to be honest I feel it is too much initially.

AN: yeah

PT: I think that… this is my opinion

AN: Yeah.

PT: other people might disagree. I feel that that is too high initially. I think it should be lowered not down to nothing but maybe to five. The one or two that I had problems with then maybe then when we talk about it that we can discuss that that’s not really working for me and not that I wouldn't rather do it, I'd rather not do it as much because I found it painful. Then work up and as we know now on quite a number of those I’m doing the amount that was first forecast and not a problem.

AN: [00:12:48] Did you feel under pressure at the beginning then?

PT: [00:12:50] No. No I didn’t feel under pressure it’s just a case of wow that’s a lot and with one or two of them there was no problem at all, no problem at all [00:13:03] it was getting used to doing one or two of the things.

AN: yeah

PT: and that was great, once I got into that into a nice flow I felt good.

AN: [00:13:18] Good. [00:13:21] Do you mind if we talk about the initial visit?

PT: No, carry on.

AN: How did you feel about being randomly assigned to the exercise program? So obviously you consented in a study where you may have had exercise, which you did…

PT: Yeah

AN: or you may have been asked just continue as you…

PT: [00:13:42] yeah, I mean the thing about it is it was made very clear that the end of the day was my decision. [00:13:50] there was no pressure put on that you know well because you got kidney problems and because you're old you've got to do it. [00:13:57] it’s something that never even cropped up. It was something that you explained was a study to try to find out if what you was doing could help people with kidney problems who really maybe didn't have as much movement, I am one of them that's got a lot of problems with arthritis and one thing and another now you might have people coming along that are my age who may not have any physical problems…

AN: umm

PT: …and to them it might seem very easy and acceptable but that's not how it was put over, it was put over for me to understand that I had a choice but with that choice only happened after we'd been talking both you and obviously the lady that was here, the physio, there was no pressure, there was no pressure, it was explained in a very easy way.

AN: So if you had been randomized not to the exercise group [00:15:12] and we just said well we're not going to randomize you to the exercise group please continue as you are doing and we'd like to see you again in 12 weeks’ time. Do you think you'd have been happy with that outcome and do you think you would have stayed on the study?

PT: [00:15:27] No I wouldn’t have stayed on, I'd have felt that it was, because the thing about it is I wouldn’t have been doing anything so I had a goal…

AN: hmmm

PT: …when we spoke I had a goal

AN: yeah

PT: and if you would it's a challenge and I like a challenge.

AN: [00:15:51] So your saying if on that first visit we’d have said we’ve randomised you you're not going into exercise but we'd like you to come back in twelve weeks because you're going to be in a non-exercise group. You would have said thank you but no thank you?

PT: [00:16:04] Yes, yeah definitely.

AN: OK. [00:16:08] and is that, what what what why? Do you mind elaborating on that for me?

PT: [00:16:13] Well the thing about it is that when it was when we talked on the first assessment you were talking about the well-being, now to me to send me away and say will see you in twelve week, I’d have just felt I’d wasted some time coming up here.

AN: Yeah OK.

PT: It would have been to me it would have been a waste of time with it because it was study, I was hoping that I would be able to help in this study for you but more for me.

AN: Yeah [00:16:56] yeah I understand that makes sense. So you were hoping that you could be doing the exercise in the hope that it would improve

PT: [00:17:04] Yeah, yes yeah even if we cut out the exercise down to five and kept them on to five right through to today that would have been better than nothing.

AN: [00:17:17] Was it clear to you that when you complete the consent form we're giving you all the study information that you might have been randomized to the non-exercise group?

PT: to be quite honest with you [00:17:29] no, I felt confident in myself that I I'd responded to the questions and the many exercises that we did here that in deep down I was hoping that I could carry on.

AN: Yeah

PT: just to find out and like everything else, I give things a certain amount of time. If after three weeks we’ll say I felt that my my health and I'm talking about my bones and my… was deteriorating because them I would’ve stopped myself

AN: But just just going back because it's important for us for the study, so when [00:18:16] when you first came and we’d spoken about this, you didn't you didn't know that you might not be doing exercises, did you think oh I will be doing exercises or?

PT: [00:18:28] well I think it I think it's all anybody's perspective, what they as an individual

AN: hmmm

PT: you know it’s no good coming up here with a defined way of, well I'm going to do this come what may but I’m not going to do this come what may. It’s talking and if you’d have said we don't feel that you're right for it, I would have asked why?

AN: yeah.

PT: and because I didn't and we haven’t, to me that's not a discussion that is important to me what is important is that you took me on and educated me.

AN: Yeah

PT: that yes we feel that you can do these exercises but without any pressure.

AN: [00:19:26] yeah, [00:19:28] I'm pleased that's how you how you felt. In terms of how the study was designed we obviously said we have some first assessments to do, some individuals are too fit for the study but most are able to go into the main study and at that point we had said that if you're eligible to continue on in the study, we have two groups we have patients who either get assigned exercise or patients that get assigned to continue as they are. So essentially we have two groups to compare

PT: yes

AN: Now when you first got involved in the study did you appreciate that we had these two groups?

PT: oh [00:20:18] yeah I understood that there was two groups but the thing about it is because I'm a positive person. [00:20:24] I didn't look at the other one

AN: I see I see I’m sorry I'm laboring the point.

PT: [00:20:27] No no no you are right for qualifying it. No I I I only looked at the positive side for me.

AN: Yeah

PT: I didn’t look at the negative side that you know maybe I'm just coming here to have a chat and no you you're not fit for it or you're not eligible, [00:20:46] I didn’t look at it that way.

AN: but going back to the point you made earlier, if you were assigned at that point by our computer software to the non-exercise group you'd have said I don't want to be involved any more.

PT: yeah because the thing about it to me if I'm not if I'm not helping myself.

AN: [00:21:04] yeah

PT: nothing to do with the study because it's about an individual person.

AN: [00:21:09] Yeah

PT: but because I was on a study, I was hoping that it was something that would help you

AN: Yeah

PT: but would help me.

AN: Thank you, that's really clear. Thank you [00:21:21] and how did you find the physical assessments that we did on that first visit?

PT: [00:21:26] bit nerve racking.

AN: Yeah

PT: yeah but thing about it is [00:21:31] you don't want to make a fool of yourself but also you know when you have people what I call is catchers in case you know toppled over, that was good because it give me a little bit more confidence because it is difficult when you know right you start here and it's going go beep and then it’s gonna go beep again and then it’s gonna go and you know you’re thinking what's this all about? But once you do it and you think well I’ve done that it’s right then we’ve got the other tests and I found I found most of them ok, there was just the one that was putting the foot in front of the other. [00:22:18] I find that's a very difficult one for me

AN: it is, it is, but you felt well supported?

PT: Oh yeah yeah.

AN: Did you feel under pressure to do anything?

PT: [00:22:30] No no absolutely not. No when I, when I, I can't think which exercise it was which is like three or four after I’ve done two I’ve said I don't think I can’t do any more and there was nothing oh go on push yourself. You didn't. You just said fine.

AN: hmm

PT: That's where you are at at the moment and to me that was you know that it couldn't be made clearer that you were happy with that.

AN: [00:22:58] Yeah good good. [00:23:00] Were the, were the instructions that we gave to you, I mean it was while ago now obviously we had a recent visit where we did some of the same assessments but were the instructions that we gave clear?

PT: Yes, [00:23:15] yes very clear. Just they wanted me to start here and walk, turn round, stop for a few seconds and then walk back umm that couldn't have been simpler.

AN: Yeah

PT: When we’ve come to do the exercises, you showed me what the exercises composed of and so I just you know I can have a go at that.

AN: [00:23:43] Good, good. So in terms of the assessments, the physical assessments you are asked to do, did you did you feel like [00:23:54] there were a lot to do, not not that many to do or just, no real thoughts?

PT: [00:24:00] I never really thought about it because it wasn't strenuous umm it wasn't a case of right you are coming in here at ten o'clock and we've got have them done by 10:15.

AN: umm

PT: it was none of that. It was a case of at your pace.

AN: Yes.

PT: And that was the thing that was important at your pace

AN: Yes.

PT: And you know yourself in some in some like a fit… like in a physio centre, they're limited to time [00:24:31] here you've just turned around and said we've got as much time as it takes

AN: yeah

PT: and with that it were case of \*phew\* I can relax.

AN: [00:24:42] Good good, [00:24:45] moving on to the questionnaires that you're asked to complete do you have any thoughts on those?

PT: umm the last block that we did [00:24:55] some of it seemed like a psychometric test.

AN: yeah

PT: and I'm not a I'm not a fan of them and I think they can become very confusing because as I said I'm not the most intelligent person but I'm certainly not stupid and I’ve done psychometric tests before and people can say what they want but I believe that it they’re done that way to try to trap people

AN: hmm

PT: I've always felt that with psychometric tests because the thing about it is that you will say one thing one way and then you'll say the exact same thing but in a different format. I don't think that is something that is very good. I mean when I went down to London for my assessment there was there was some kind of psychometric and [00:25:54] yes it worked for me as much as [00:25:57] how can I [00:26:00] put it I didn't feel that I needed to have a psychometric test to know who I was

AN: yeah

PT: and after that the talks I had with the two psychiatrists that I was under and they both both said in unison this person is female

AN: umm, umm

PT: the psychometric is a little bit I don't know [00:26:28] it's a bit divisive

AN: [00:26:31] when you say psychometric what do you mean by

PT: psychometric is a number of questions, it’s to find out, it’s to trip you up in some respects, not in a nasty way but in some cases it is and I’ve had that that if you say the moon rises at seven o'clock at seven o'clock and you've changed that round it's going to be the same answer but sometimes people read things different and with that you get a different answer when you shouldn't because that question is that exactly the same question so you should get the same answer.

AN: [00:27:20] So the questionnaires that we asked you to do were not meant to be psychometric tests erm [00:27:33] they were, they were meant to be assessments, well they were they were different actually assessing different things. We had one that was assessing the quality of life

PT: Right

AN: another one that was assessing symptoms and your symptom burden we call it. We had the falls concerns questionnaire; we had the questionnaire on your ability to do everyday tasks.

PT: hmmm

AN: [00:28:06] and then there were that two that I was asking about your physical activity and also about the questions about fatigue.

PT: hmmm [00:28:18]

AN: Now what I’m perhaps hearing and again I don't want to be kind of putting words in your mouth and correct me if this is not the case but it perhaps sounds like that you felt that or did you think that there was overlap between did you feel like you've been asked the same question but in a different ways? Is that what you…

PT: yes.

AN: Is that what you think?

PT: Yes and that's psychometric

AN: [00:28:46] yeah.

PT: And and that's but it still didn’t put me off

AN: sorry?

PT: it still didn’t put me off, I was still willing because as I said not the sharpest knife but I'm not stupid and with that I can look at the question, I can answer it then as I'm going down whether it will be on that paper or next paper and think hang on that’s exactly the same question but in a different way.

AN: [00:29:12] Yes, so do you think that you were asked to do too many questionnaires?

PT: yes

AN: you do? [00:29:19]

PT: yeah I think I think I think that it was it wasn't necessary, I think the most important thing about this is how the person or persons feel when they initially start...

AN: Yes.

PT: …of what the outcome is for them is and how they feel…

AN: hmm hmm.

PT: and I don't think it needs a lot of questions. I think straightforward talking like you know I'm straight forward and if I'm not happy with something I will say it. I think that's the, I really believe that what we're doing today is far more constructive...

AN: Yes.

PT: than destructive, it’s good.

AN: and you think that it’s better than…

PT: yes [00:30:13] without a shadow of a doubt.

AN: The reason why there are questionnaires like that used is because it allows studies to compare against each other in a way.

PT: Right

AN: Because if each study uses the same questionnaire you can say well and they all have scoring systems you can say well that questionnaire of that score has changed from this to this so then you can try and track a change and then if other studies are doing similarly you can have a bit more of a comparison. [00:31:00] Equally I agree that having a conversation like this perhaps provides richer information.

PT: [00:31:11] well the thing about it is you're talking one to one

AN: hmmm

PT: and if there's something that I say is not saying wrong but you don't really understand it, you can ask me, vice versa.

AN: yeah

PT: now with that there is either basically yes or no. I'm sorry, [00:31:34] that to me [00:31:35] is, there is too much paperwork today throughout

AN: yeah

PT: emm because we have forgotten how to speak to one and other, like we do you know and that that to me is that the important thing

AN: hmmm

PT: when I get a negative vibe from somebody and I'm not saying this is for other people but this is for me I turn off

AN: yeah

PT: [00:32:05] and I'm not really bothered about what they're talking about I just want to get the hell out of there.

AN: yeah

PT: [00:32:11] but if it's meant very simple then to me as I said because I understand psychometric test and because I understand that because there was I mean how many pieces of paper were there last time I was here? Five were it? To me it wasn't necessary

AN: No

PT: I think a 10 or 15 minute interview just on them would have been enough.

AN: yeah

PT: now this is a totally different thing because we've given, I'm giving an interview on how I've gone on the whole thing.

AN: Yeah.

PT: and then they were were to me they were boring.

AN: Did any of the questions make you feel uncomfortable?

PT: Yes there was a couple but there was, it weren’t uncomfortable, it were like really? Do you really need to know this?

AN: Did you recall which?

PT: [00:33:13] No I don't because there were that many, you think how many questions there was on them forms.

AN: and did you feel like anywhere, feel some were inappropriate?

PT: [00:33:23] Yes, yeah I think it's something that it could be looked at again

*[Excerpt deleted to maintain confidentiality]*

AN: Yeah

PT: I had to change some of it and it wasn't because it was bad but it was how it was worded.

AN: yeah

PT: and I said that's not acceptable due to the fact of and with that I then said if you do that then I'll sign off on it. And it was done and I signed off on it and it went on the Internet and I think that's the thing that's important.

AN: hmmm

PT: that the people can understand everything, not just about coming here and doing one or two exercises to have an initial you know to look at the people, to understand and the paperwork is to me secondary.

AN: Yes.

Pt: The most important thing is me as a person, not what [Participant name] said on this.

AN: Yeah

PT: that to me is not important, it's what I speak [00:35:01] that's important

AN: ok that makes sense. [00:35:07] did you find it was hard to keep your concentration during the questionnaires because there were that many?

PT: [00:35:14] Yeah yeah I got bored, I were ready for throwing them in the bin if I were honest. If there were a bin next to me I think you would have found them all shredded because it was just too much.

AN: [00:35:26] did you feel that you weren’t well supported during doing them?

PT: well it’s nothing to do with support it was a case that I felt I felt challenged beyond my understanding because to me a lot of it was just you know tick this, tick that or is that a three or four? Oh I don’t know, oh I’ll give it a two instead because it just got intense and that’s something I don't like.

AN: yeah no [00:35:57] that's really useful information and we definitely definitely need to look at that erm you may be or may not be surprised to hear that in its original form we had more questionnaires.

PT: [00:36:09] Oh goodnight

AN: we did we we we we changed some

PT: you better change them again as well.

AN: Ok, we have spoken a little bit about the exercise program but would you mind if we came back to it.

PT: [00:36:26] No

AN: [00:36:30] so firstly thinking back to that exercise education session you had what were your, what are your general impressions of that? How did it go for you?

PT: [00:36:41] Fine fine because everything was explained to me before I actually started and knowing that there was support that was important as well.

AN: hmmm

PT: because the thing about it is that you can get a little bit, not because of your illness or because of your disability, a lot of it is because it's like being on the stage all of a sudden, you're the centre of attraction and you can get a little bit giddy and that's why I felt a bit uncomfortable on my feet.

AN: hmmm

PT: Not that it was a pressure, it was a case of I need to do this and I need to do that and once I’ve done it I am like \*phew\*, that’s good because I didn't want to find that halfway through that I was really struggling because I wasn't. But there was yet again there was no pressure put on me how quick I had to do it and to be quite honest with you whatever you ask me today it will be you, I will give you the same answer at no time on this study was I ever put under pressure, anytime, excuse me, anytime.

AN: good

PT: So that has made it, even to come to do this, where you kept saying well you don't have to do this, I want to do it emm and it’s only because of our relationship and what I've learnt from it.

AN: [00:38:17] Good good. [00:38:21] Did you think it was helpful having a physiotherapist teaching you the exercises?

PT: [00:38:26] Yeah well if you remember what I said when we first sat down, you said this is the physio well she can go because that's how I am like a bit of fun.

AN: yeah

PT: [00:38:35] but the thing about it is that she was very very helpful emm she was sympathetic to my disability

AN: Yeah.

PT: and that was lovely.

AN: Yeah.

PT: That was something that I find is something that is very good when you get somebody that you've got a warmth to that is there to help you and not to well you need to do this and you need to do that, she didn't. She was just very helpful.

AN: [00:39:07] And obviously you being new to exercise, did you find that the exercises were explained to you in sufficient detail? Did you go away on that day thinking I can do these, I know what I'm doing or?

PT: [00:39:24] well, like everything else it it’s something new. I didn't know until I tried.

AN: Yeah

PT: what I did here was just a little bit.

AN: Yeah.

PT: What I was going to do was a heck of a lot more when I got home.

AN: Yeah.

PT: So initially when you look at, my god is that how many I've got to do? Three times ten me right leg, three times ten my left leg. I'm never gonna do that.

AN: hmmm

PT: Because I didn't do that here.

AN: hmmm

PT: So it was daunting.

AN: Yeah

PT: that's why I feel would be bit better

AN: Yeah

PT: maybe not in every case but in some cases that you just cut that down initially.

AN: Yeah.

PT: and then if you talk to like you did every week spoke to me even if it's a case of right well go down to five and then after a couple of weeks say well can you make it to six or even seven but don't go above 7 and do it the way that we did and I found that was the most helpful way

AN: [00:40:34] Good. [00:40:37] what did you think about the actual exercise guidebook? Did you find that useful or?

PT: yes [00:40:43] because the thing about it is that you could look back on initial what you had actually done but the thing about it is there was no there was no pressure about putting it down once I understood the scoring. That was a little bit confusing initially but that that's something that…

AN: the exertion score?

PT: [00:41:07] yeah yeah, [00:41:08] that that's a little bit confusing for me because I thought you wanted me to get to the big numbers where you were saying no if you are doing that it means you're doing too much.

AN: hmmm

PT: You're you know you're pushing yourself too much. Once I realized that it was a case of right what’s the standard feeling, well some days that is a 10, some days it's a 13 because I don’t feel as good today. So that was that was good because that was self-assessment and that was good as well.

AN: [00:41:48] so the fact that you are able to say that this is how hard I found it…

PT: Yeah, yeah without a doubt, without us having to talk about it on the phone well how did you go on with exercise one? You know we didn’t need to do that, it was a case of exercise one emm 3 by 10 oh doesn’t work because that’s the walking but say number two three by ten, [00:41:54] that was good, I had a good day today. And then looking at the whole program of how long it took it that didn't really bother me as much. It was making sure that I was doing what I felt was necessary for me. Without without like having a teacher you know cracking you up, no you've got to do nine today, you got to do seven of them, it was a case of I could choose and then work up

AN: hmm hmm.

PT: and that to me was, that's the right way to me of doing a study, giving the giving the patient ample opportunity to do what's best for them.

AN: [00:43:06] yeah good. [00:43:10] Do you have any other comments about that first visit, the exercise session? Anything that could have been better or anything that worked well or?

PT: no [00:43:19] I think I think it was a very straightforward assessment. There was nothing strenuous.

AN: It wasn’t too long [00:43:30] first session?

PT: no no no

AN: It does end up being up to three hours usually sometimes when you factor in the exercise teaching session but you found that was ok?

PT: No no no, that was fine was that.

AN: Now moving on to the actual exercises, I think we’ve covered a lot of this already actually, one of the questions that I have is were you able to perform exercises regularly at home?

PT: Yes. Yes.

AN: and you've already said that it was the flexibility to begin with to kind of build up to doing… aiming towards doing three sessions a week

PT: Yes

AN: and I'm aiming towards doing so many repetitions of things.

PT: yes

AN: [00:44:26] Is there anything that helped you to exercise?

PT: emm motivation, self-motivation

AN: and what gave you that? What was what was driving that for you?

PT: Wanting to believe that [00:44:42] I could get a little bit better mobility, certainly with the, because a lot of them a lot of exercises are to do with your legs, [00:44:51] there’s only really one is to do with your arms and that’s the wall press ups, rest of them basically for legs and when you’r first doing it, especially the marching, you think oh this is stupid, but when your getting to the end of it your thinking oooh my muscle are bit sore but sore is good, it means that your working something that you haven’t worked before so that wasn't a problem doing 60 of them because it's 30 on that and 30 on that.

AN: ummm

PT: I’d no problem with that. The toe lift, no problem with that one. The stretching out of the leg is a little bit more difficult because of my knees but that was okay. The one against the wall that was that was tough because my muscles in me arms and everywhere never been used as much for

AN: I think if I recall from our conversations you said that was the one you enjoyed?

PT: [00:45:58] Oh no I enjoy doing it, it was good but then there is were like phew but it was phew in a nice way you know that I felt that my muscles were actually getting a little bit stronger.

AN: Was that your favorite of the exercises do you think?

PT: emm I think for positivity possibly yes.

AN: yeah, is that because you felt most able to do that one or?

PT: [00:46:23] Well no I felt I felt able to do you know I think there’s 4 [00:46:29] out of the 6, even though walking I found difficult because I find walking anyway. But I think now because I've done them I'm not as I'm not as afraid of walking as I was but it still gives me a lot of problems emm the standing up sitting down that's a bad one for me. I don't like that one at all

AN: and that was because

PT: emm well it just absolutely wrecked my knees. I couldn't do it. I did one and sat down and on the second one I was starting to struggle.

AN: [00:47:15] so you say it wrecked you knees do you think it may, obviously we've spoken before about your arthritis in your knees and your previous knee replacement.[00:47:24] Do you think it made your knee your knees worse during the study or was it just?

PT: [00:47:30] No I don't think. Actually I don't think it made them worse. [00:47:35] I just felt that the pain the pain was acceptable in so much as it’s something that [00:47:44] I have accepted for quite a long time.

AN: yeah as part of everyday life?

PT: yeah. But the thing about it is because it's an exercise I am trying to do. alright I mean I know the maximum was five times three, but that wasn't, I couldn't do it, it was impossible. I felt I felt weary, I felt [inaudible].

AN: [00:48:12] did you find that even though it was causing or did cause some discomfort, [00:48:18] did you find that it was a benefit to you doing that exercise at all or do you think that?

PT: [00:48:24] Yes it helped here, it helped with them. It didn’t help there [00:48:28] but it helped because at the end of the day…

AN: your thighs

PT: the thighs are getting stronger.

AN: Did you feel like you're getting stronger?

PT: with my thighs, yes, [00:48:37] yeah and I have done with my arms.

AN: so during the study have you felt like there’s been an improvements in?

PT: Oh yeah. [00:48:45] without a shadow of a doubt. There's definitely been even though I am wrapped in pain most of the time I feel that there's better quality within my legs and certainly my arms and it's just that, like now, I mean I could do this I could do this all day.

AN: [00:49:10] yeah so do you feel like your mobility is better than it was when you first started or just the same?

PT: yes, [00:49:16] yeah not much but there's certainly definitely some quality there.

AN: yeah [00:49:22] and do you think has the knee pain, the discomfort in your knees, has it got better or worse [00:49:28] or just the same?

PT: I think it's like everything else that would be a silly question to answer for me because some days are a lot worse than the others.

AN: right ok

PT: Today is not a very good day but it's not the worst but it's certainly not the best.

AN: [00:49:45] did you find, did you discuss the exercises with a family member or friends? Did they help in any way?

PT: No.

AN: Is this something you just did?

PT: no this was about me.

AN: [00:49:57] Yeah. [00:50:02] Part of the study is looking at the safety of exercising at home in this way, I mean how did you feel in that regard at home, did you feel safe doing them? [00:50:14] do you feel comfortable or did you?

PT: at the end of day I think each person's got to take their own responsibility. I don't think any information or any cajoling from you and I don't mean cajoling in a bad way.

AN: hmmm

PT: each person has got to take their own responsibility. If you start doing exercises you've got to know when it’s right to stop them

AN: hmm

PT: one your brain will tell you.

AN: yeah

PT: but more than anything else thr discomfort will tell you. So to me I don't really think that comes under the study or comes under your responsibility. I believe that that's the responsibility of the individual.

AN: yeah, ok. [00:51:01] did we give you enough information I mean you probably would have known this already but at the beginning to say this is when we think you should exercise and this is when you should stop?

PT: [00:51:13] Yeah, [00:51:13] Oh yeah. Oh you made that very clear, you know it wasn't a case of when to do it was a case of if you're doing one of them exercises doesn’t matter which one and half way through the set you feel uncomfortable or it's causing you problems then we advise you to stop.

AN: hmm

PT: now that was important as well.

AN: Did it feel like you were getting permission then?

PT: Yeah. Oh yeah. Yeah I think that was important. I think the phone call every week was also good.

AN: I was gonna ask you what you thought about that?

PT: In fact [00:51:52] the thing about it is that we could talk about well that one I am really struggling with, that one not a problem with. [00:52:01] and with that you could then assess because this is your job as an assessment to assess people and say right well drop that down to whatever, that one do you think you can do a couple more and with that I could answer honestly and say yes I think I could take that from five up to maybe eight. And you always compromise said well don't go from five to eight go five to seven. See how that is and then the next time you do it in that week if you want to do eight then try it, see how you feel. And it was always put on me how you feel because at the end of day I can be doing the exercises but you don't know how I feel, it's my body. So a lot of it is actually down to the individual person to actually monitor themselves.

AN: yeah, [00:53:06] If if we didn't have those weekly phone calls do you think you'd have, do you think that would have affected how you'd have been involved?

PT: maybe, maybe [00:53:15] I think every time that we spoke it was another little, well they’re interested, they really want to know what's going on.

AN: Yeah.

PT: So with that it meant that you were concerned that I wasn't doing too much, on the other hand that you didn’t want me just to do two or three of every one and just say well that’s it. That was important. Yet again that's down to the individual person. The person that you know with something like this have got to take it in their own mind and body…

AN: Yes

PT: that is their responsibility not yours, your responsibility actually ended after [00:54:03] the first time I came here. After that it's up to me [00:54:08]. But what I can do when you ring me, I can say I'm struggling with this, you are a professional can turn round and say right don't do that this week or next week we’ll drop it to whatever and then we'll see how you are in a couple of weeks, see if you can up it, so there was no pressure.

AN: Good.

PT: and I think that's why the phone call helped.

AN: Yeah.

PT: Give me that little bit extra drive because at least I’ve been able to say that one Andy is not really right. Right well cut it down and that to me was the most, that was the best part about it.

AN: yeah [00:54:50] good. Yeah, that’s great. [00:54:51] Is there anything you'd like to discuss about the exercise program or the study in general? [00:54:59] Anything else?

PT: No I think to be quite honest you I think it's, on the initial exercises of understanding them is very very straightforward and once you read the literature that you take home with you and read it properly, not just to skim through it, but to read it right, this is exercise one, it’s walking, don’t like that one forget that for a minute, I know I have to do it but exercise 2 is that. Now this is what the guidelines are [00:55:39] and this is right can I do that? Right let’s have a try at that. [00:55:44] And with that you've got something. That's why I've kept it because it's something that I can go back to and say yeah wonder if I could up that one up to 15, that will be my choice but also know that that's too much. Because like I said self-assessment, you've got to be able to, you've got to be able to self-assess with these things as much as help I can get from you as a doctor and as a physio or whatever, it's still down to me.

AN: so [00:56:24] if you think back to before the study where you weren’t really that active to being active during the study, do you have plans to keep being active going into the future?

PT: [00:56:34] Oh I still do, I still do some exercises without a doubt, you know, the main ones is the ones where I’m sat down and I’m…, because this is the important that my legs are…, because the thing about it is that because of the problems I have with my knees it’s so easy of just like oh well I can't be bothered but I want to try to do a little bit just to see if I can you know keep that up.

AN: Yeah

PT: The arm one isn't as important because I don't have problems with my arms even though I'm as weak as a kitten. Emmm I used to be, I've never been a strong person but I could handle myself when I was working to you know lift things, I can’t now, I can’t now, it's just impossible. Just getting a couple of bottle of milk and that even that I find hard now compared to what I used to do but that's not important. What's important that when I get out of the car and I go shopping, alright so I’ve got a trolley so I've got a balance, that I'm not struggling.

AN: hmmm

PT: And that's important, these babies keep going [slaps legs] because at the end of the day my big problem is my kidneys, end of story. And with that, I mean when you think about it two and a half years ago I was lucky to survive that you know I could’ve quite easily died that come from five consultants all said the same “you've been very lucky”

AN: hmm.

PT: But that was to the credit of the people on the ward and also all the consultants and all the doctors and nurses.

AN: yeah

PT: [00:58:37] So you know, I know it upset Dr XX quite a lot because being on the level round about 30 all of sudden I were down to seven but managed to get it back up to thirteen, [00:58:55] twelve, thirteen and it's been steady ever since.

AN: hmm

PT: But I know he was upset that you know that I was so ill because I don’t think he realized just how ill I was. So I’ve had setbacks in that respect. But at the moment touch wood I keep I keep that and with these exercises it also, it also helps with the blood flow.

AN: Yeah.

PT: Not a lot because you know it's not a case of I'm running or doing anything like that. That's the last thing in the world I could think of doing and yet I used to love running and walking, absolutely loved it.

AN: [00:59:45] Do you think the exercise has or could have beneficial effects on your mood?

*[Excerpt deleted to maintain confidentiality]*

PT: Having tinnitus doesn’t help, I’ve that since I were 18.

AN: hmm hmm.

PT: had that 50 odd years, that doesn't help, even though I have got hearing aids in emm I still struggle [01:01:48] erm so there is that so when I do my exercises, I seem to go in another another place.

AN: hmmm

PT: Because I'm concentrating on what I am doing because I am counting 1, 2, 3, 4 you know I'm counting so with that I'm always in a good place. While doing all my exercises and it's not really working then instead of getting upset or angry I just don’t do it.

AN: hmm

PT: I can come back to that maybe in an hour and do it again you know so no it I think there is possibility that the exercises have helped me with my mood swings but at the end of the day Andy if I'm totally honest their neither harming nor helping, that’s to do with me, that’s to do with me psychologically

AN: [01:02:53] Hmm hmm.

PT: That's why I am on, you know

AN: [01:02:59] Maybe this is more of a distraction?

PT: Yes yes [01:03:03] yeah that's why I watch television so much. And I mean I watch cricket, emm like if you’d have said like oh it’s gonna be this afternoon it’d been you can coco, cricket’s on you can coco.

AN: well with that in mind.

PT: No I'm fine, I'm just you know I'm mindful that the information that I'm giving, instead of running off at the mouth which I can do, is something that you found helpful.

AN: [01:03:32] definitely absolutely it’s been really really helpful [01:03:35] and I think your comments been very insightful and I think it’ll be really helpful as we move forward and try and develop things further

PT: good

AN: genuinely [01:03:51] before I end the recording is there anything else you want to know or?

PT: [01:03:55] Oh well what I will say is if that though at end of the day I’m only a study if you feel that you want to call me at any time to maybe help you with something that you know, all you got to do is ring me, you've got me number.

AN: that's really good of you, that's really good

PT: yeah I mean think about it is even if you just want to chat over the phone or we’d like you to come up because you know we have two or three people who are interested in what you want to say because they've got questions emm if it will help you then just feel that you’ve all you've got to do is pick up the phone.

AN: [01:04:37] that’s really kind of you to say and what I would say as well if if you were wanting to get more involved in research as a lay person, there is a layperson research group here that meet regularly and they're really valuable actually providing insight and perspectives on studies, particular those in the design phase emm it's something to think about it, if you are interested.

PT: [01:05:08] well send me some pictures and let me look at it. I think you know.

AN: I will see if there is something, I can double check before you go away today.

PT: well you can just post it off to me and just you know give me chance to peruse over it.

AN: yeah, I don’t know if there is any…

PT: well I would have thought there should be because at end of the day if they are meeting…

AN: Yes.

PT: it’s not that you know we're not talking about secret service

AN: [01:05:39] No no, I'm not sure if they’ve got a flyer or anything it might not be like that but

PT: well I would've thought that you know if they want to encourage other people, I would've thought that that's something that they should have.

AN: [01:05:46] Yeah

PT: And if they haven't got it they need a kick up the backside or the trust to get something done

AN: and maybe that's you'll be a good person to

PT: [01:05:58] oh I can upset the people, I can upset people, your main boss Karen can tell you I can upset people.

AN: [01:06:08] Well I'm going to end the recording now.

PT: OK.

AN: and thank you again.

PT: No not a problem.