**Parkinson’s radio pilot: diet and exercise (personal experiences segment)**

**Exercise discussion- Duration: 11:55 (Please note that this is the raw, unedited audio file so there are instances of crosstalk, pauses and input from others)**

*Host: Andy*

*Guests: H and D*

Andy: Ok so, I’m here with H and D and we’re talking about exercise and diet. So the first question we have to get the discussion going is “what exercise to do you take, what are the benefits and obstacles?”

H: Shall I start (crosstalk with Andy)

Andy: we’d love to hear from you

H: I go to the gym twice a week, I go for walks with a walking group and those are the main things

Andy: I think you’re getting a prompt there; do you want to say that?

Other: you can say it

Other: (whispers) Aggie

H: Oh, and conductive education, sorry, I’m forgetting about that

Andy: conductive education?

H: yes, there’s a version of it specifically for Parkinson’s patients, it’s a system that was developed in Hungary after the Second World War to help rehabilitate soldiers who had been injured.

It was found to help stroke victims, as well and children with cerebral palsy and finally Parkinson’s victims. It’s based on training the body to use new nervous pathways in place of the ones that are damaged. It hasn’t had medical trials and so on but it seems to come quite well recommended by the medics.

I’ve had quite a lot out of it. They teach you to write again and my handwriting had just about disappeared. They make you learn right back from the very beginning again, triangles, lines circles, both hands, and my writing came back.

Andy: Oh fantastic, and is that something that you’ve got experience with as well?

D: I have yeah, I’ve just recently finished a course of conductive education with Aggie and I found it very useful in terms of keeping my balance and movement and it’s advised to do the exercises at home but I tend to find I do it better when I’m actually with Aggie. I also have just joined the gym again, I go to the gym, a program for people with Parkinson’s, I also do tai chi, again for balance and so forth and I feel it has improved it. I also take to dog for a walk, or he takes me for a walk! I have a German shepherd, he’s 5 years old and he gives me great exercise, usually for about an hour and a half a day, which is quite a bit.

Andy: and any obvious benefits or obstacles to taking part in different things? It sounds like you need someone there to motivate you to do the exercises, is that right?

D: I think it’s more a case of seeing I’m progressing, so it’s useful to have her there to say I’m doing the right exercises in the right manner, and that will be something I’ll supervise on this course I’m going to do next week, twice a week

Andy: could you give me an example of some of the different types of exercise that she gets you to do?

D: going from standing up from a chair, getting you to walk backwards towards a chair, getting in and out of bed, which is something of great difficulty. Squatting, doing half squats, walking the ladders

Andy: walking the...?

D: ladders, walking the tape, she has this ladder which you’ve got to miss a step, you’re in a line with other people, you’ve got to step across them towards her. When you walk the tape you’ve got to try and walk in a straight line to see what your balance is like and then you’ve got to do some power walking to make sure than you can still get a quick shuffle on if you need to.

H: the backwards walking, you know it’s a matter of learning a discipline almost. You have to look behind you, both ways, turn your neck as hard as you can because that’s the only chance you’ve got to see that you need to take a full step backwards and sit and if you’ve not looked round properly, you miss. So you’ve got to make sure that you do that.

I think the ethos is that you’re not allowed to sit around and feel sorry for yourself. The word “can’t” is not allowed, you’re not allowed to say that “I can’t”

D: you come away physically drained, I do

H: yes

D: I’m ready for a sleep when I get home

H: I’ve sometimes De that, come home and had a sleep which is strange because it’s not using up a lot of calories, it’s not aerobic particualry, but the concentration required is quite high

Andy: is it similar exercises that D was describing that you do as well?

H: yes

Andy: is it tailored for each individual?

H: it’s tailored to...they do classes for stroke victims, for MS aswell and for Parkinson’s and I Don’t know what the difference is because obviously I’ve only been in the Parkinson’s ones, so I guess the others are similar in some respect

D: it would be helpful if they could come to the area rather than trying to get across with traffic in the morning, that’s to only problem I find

Andy: where is it based?

D: it’s at Jesmond

Andy: so is it not available everywhere?

D: No just there

 Andy: so how did you find out about that?

D: From the Parkinson’s nurse

H: same here

Andy: my producer was trying to tell me something a minute ago...the benefits. Ok, what are the benefits for you of conductive education?

D: confidence, balance

H: posture

D: posture, using your muscles again, especially I find your thigh muscles, because with the squats and things like that you can grow some size back in your leg muscles to give you some power, which you lose if you Don’t... you wouldn’t do it normally, unless Helga was there

H: I don’t know if it’s worth mentioning the clinical trial that vie De, the Speedflex system of exercises. There’s a different objective there of cardiovascular fitness, Vo2 max sort of stuff, and that’s to exercising at a level that gets your heart rate nearly at a level that’s maximum as possible and the results for fitness I think are really quite spectacular, but its specialised equipment and supervision so I’m not too sure how people would have access to it but the results are fantastic.

I lost in 12 weeks 2 inches off my waist, half a stone, eating like a horse, physical fitness it really does bring it on but the limitations are the availability that’s the problem.

Andy: and do you have experience of that, of the Speedflex?

D: I haven’t done the Speedflex

Andy: is that something that would be suitable for you?

D: I haven’t heard much about it actually

Andy: so how did you hear about that one?

H: I got a call from the Parkinson’s service, asked me if I would be interested in a trail and the first one I did was under Ailish O’Callaghan and that was sort of conventional gym more or less, which produced its benefits and this was a study with I suppose more extreme exercise. After every set you couldn’t do anymore, it’s very very tough

D: so it’s like work to failure, were you working to failure?

H: in the sense of couldn’t go on?

D: couldn’t go on any further

H: well I’m not sure if that was deliberate but that’s how I felt and they ramp up the level and intensity and it’s short periods of very intensive and then a very short rest and then another period of very intensive exercise but that boosts heart, lung capability.

A benefit would be in the long run what carries us off, I’m told Parkinson’s doesn’t kill us directly, but a lot of chest infections and so on do and it improves your lung capacity and your physical fitness. So my heart rate went down to the 50’s, my pulse, blood pressure 102 over 59. I had nearly the same weight and blood pressure as I did when I was 21. I’m a lot more stupid but eh...

[laughter]

Andy: so is that something you would be interested in D?

D: yes

Andy: you mentioned that you had joined the gym

D: Yes, I did a course at the gym, I was referred by the doctor, there’s a referral system at the doctors and they put you in touch with a gym...it takes weeks to sort out mind, going from the doctors to the council, the council passes it to their doctor and they have a program for you for different levels of fitness.

Andy: when was that?

D: I think the first one was a cardiovascular, the next one’s weights and the last one’s stretching. It’s very, very reasonable; it works out about £2 a session which is quite good.

Andy: and have you seen the benefits from that?

D: I haven’t started yet, I start next week

H: where is that?

D: Ashington leisure centre

Andy: Ok, excellent