HWM08 11-Dec-2020 Interview Transcription

RB: Ok those are recording now. So I have, I always use two just to be on the safe side

HWM08: Yeah, that's fine

RB: Ok, so what I normally start off with is by going through 2 questionnaires about AF symptoms and quality of life

HWM08: Ok

RB: Um so if I just go through the, er, questionnaires – we don't have to stick to it rigidly but it just gives a bit of a guideline about what things you might be finding with your AF.

HWM08: Ok, that's fine

RB: So the first thing on the … The first questionnaire is called the University of Toronto Atrial Fibrillation Severity Scale

HWM08: Ok

RB: And the first question is your gender, so can I ask how you identify?

HWM08; Female

RB: And can I ask your year of birth

HWM08: 1960

RB: And then the next question is are you in AF currently?

HWM08: No, not this morning..

RB: Do you know when you're in AF?

HWM08: Sorry I didn't hear that, sorry

RB: Do you know when you're in AF?

HWM08: Yes I do

RB: You feel it

HWM08: Yes I do

RB: And how do you feel about your life at present? This is a 1 to 10 scale from 1 being the worst possible life to 10 being to best possible life

HWM08: Seven

RB: Seven, so that's pretty good. So what things contribute to that seven, what would make it higher and what would make it lower?

HWM08: Ummm, well I've just had an ablation for the second, I've just had a re-do of my ablation so that's hopefully … and I'm still on my .. what would help alleviate and make it better would be actually coming off all my medication, otherwise… but actually it's only like three weeks since I had my re-do and I know that.. because last time it lasted pretty well without medication for about two years, so um, you know, so that would be a good, that would be a good aim for me. And also to be fitter, and not be breathless, so er those two things, but one, the first one would be actually trying to alleviate some of the medication I'm on. I'm only on two lots but, you know, to have none would be great.

RB: Would be better, yeah. Are you on anti-arrhythmics?

HWM08: Yes, I'm on bisoprolol and flecainide

RB: Ok, sure, and how long have you got to stay on those, have they told you?

HWM08: Yeah, they said two to three months. I had a bit of a hiccough with my ablation this time because I had a bit of pericarditis so I ended up being admitted to my own hospital which is like, not a good idea, and you know.. ended up being on, is it chlo..? One of the anti-gout medications to help alleviate the pericarditis. It's fine, I'm mean I've been back to work two weeks now but it was a bit of a hiccough. But it's fine. It's fine.

RB: Yeah, of course. Of course.

HWM08: Yeah

RB: So on average how long do your irregular heart.. how often, sorry does your irregular heart rhythm occur? From.. So it gives a scale, but you tell me

HWM08: Um.. On a normal week at least two to three times a week. Um, but that hasn't happ.. but actually it seems to have kind of calmed.. it's since last week if anything it seems to have calmed down quite a lot, so.. because I do notice it, I feel like I.. not an aura but it does obviously take your breath away and make you feel quite rough , you know not for long but for a while, you know. So two to three times a week is quite common for me, it can be up to five or even more and it has, it was like that up til around September time

RB: So do you feel like it's calming down since your ablation then?

HWM08: Yeah, I think so. I mean things were obviously quite raw and quite inflamed and a bit rubbish for the first week or so but after that.. this weekend and maybe end of last, definitely this week seems to have calmed down a lot, so that's quite good.

RB: Then the next question is on average do the episodes of irregular heart rhythm last continuously, for several days, for a few minutes?

HWM08: Um for a few minutes but obviously for over several occasions, so per day it could be two or three times per day but it only lasts for less than two to three minutes

RB: And do you feel, you sound like you find it quite debilitating in those few minutes

HWM08: Yeah, yeah, you suddenly feel like you're either going to faint or you feel.. I mean you feel quite short of, I do get short of breath with it so it's that feeling like you're actually going to fall, or feel like you're gonna, you know, you're out of control. It's going to sound like a weird thing to say but it is that kind of a, few minutes you really are feeling a bit "bleugh". Which is not a scientific word but it's er, [laughing] it's not a scientific word but you know what I mean..

RB: It's a great quote for my masters though

HWM08: "Bleugh" [laughing] she said "bleugh", yeah. So it is that it's like you feel oh god, I don't know what, and you can't do anything about it, do you know what I mean? And I like to be in control at the best of times so when you have.. out of control it's, yeah, not good.

RB: I know but feeling out of control of your body's a horrible sensation

HWM08: It is horrible, it is horrible, and it's often.. and it can come on at any time so if I'm at work or at a meeting.. it's never happened when I've been like driving or anything like that. And it can happen when you're not.. when you're resting, which is like, do you know what I mean, so it's not always.. things trigger it, I'm not sure what things trigger it but, um, you know, so it can be like that. But it's really like you're somewhere you haven't even got a chance to be away from anyone noticing you're not very well, you know so.. You have to hide it, I tend to obviously always hide it as well, so you don't want people to know you're in AF. So I think oh my god! Especially people my office who are nurses, they're not going to take much notice really [laughing]

RB: [Laughing] It's just AF, you know

HWM08: Carry on!

RB: Does it affect you at work? Does it affect your ability to do your job?

HWM08: Um no, it doesn't affect my job, no, because as I say it's very difficult to say when it's going to happen, so does it affect.. no, it doesn't really. I have, from a sickness point of view , I haven't been off sick, only for these two weeks, like, only when I've had ablations and stuff. I mean I have had quite bad AF when I've had um,.. I'm asthmatic so when I've had a chest infection and stuff like that it tends to trigger my AF so that's one thing it does do, so er..

RB: Yeah ok.

HWM08: Do you mind if I just bear with me two secs, do you mind if I put you on speaker because I can hear you better, is that ok?

RB: Yeah of course

HWM08: Ok I can hear you now so is that ok? Can you hear me?

RB: Yeah, can you hear me?

HWM08: Yeah that's fine yeah thank you

RB: So the next question is how severe was your most recent episode of irregular heart rhythm, from 1 to 10 with 1 being not at all severe and 10 being extremely severe?

HWM08: Um, about nine. So it was really.. I lost my breath and I actually felt.. you know I had to lie down for at least 40 minutes afterwards which is very severe

RB: Very severe, yeah

HWM08: Yeah and it was, er , it was in the end of September, yeah, so quite yucky. Yeah that was home, I was at home, I wasn't at work or anything so I wasn't doing anything in particular, nothing that you could say oh that exertion or anything else kind of triggered it, it didn't really.

RB: Sure. And then thinking back to your very first episode of AF, can you tell me how it started and how severe that was?

HWM08: Ok, um, I didn't know I was in AF. I had done – you can put this in your quote actually, um. It was Christmas time 2011 and I had been on call all weekend for the hospital, but it was after Christmas. I am very large, but not as large , I wasn't that large at the time and I'd been really quite good with my diet, I thought I'd put on maybe half a stone. So I thought I was breathless because I'd eaten too much at Christmas, so, that was my.. going up and down the corridors on call and realising that had taken my breath away, and what I had was severe AF and a bit of VT at the time, SVT sorry, and a severe pneumonia

RB: Oh wow, what a combination!

HWM08: Yeah, it was when, so we're talking 2011, we had.. what do you call it, what was the flu, swine flu. We had, we'd had quite a lot of patients in with swine flu and I'd been the on call matron for the weekend, and I hadn't been nursing patients but I'd been in the hospital all weekend. I just presumed it was a) I'd eaten too much over Christmas, that was my first... guilt constantly always, so even though I don't know much about it guilt's always come in and I just presumed it was just short of breath from just being overweight, and eaten too much over Christmas, but and it was that and then pneumonia, so I had pneumonia that clipped in, and I didn't know I had AF. And it was diagnosed, and er, my cardiologist was on call. The cardiologist medical consultant was the cardiologist on call so that's how it starts with me being under Oxford and everything else. Yeah, yeah. Pretty much ended up being admitted and er, yeah. And I kind of thought it was the swine flu. Christmas cake and the swine flu. Not the alcohol! [laughing]

RB: No , no it's never the alcohol! [laughing]

HWM08: Never the alcohol. Just the Christmas cake and a bit of swine flu, that'll do. So that was it really.

RB: So just, if you had um.., it sounds like you were able to carry on with what you were doing at the time…

HWM08: Yeah

RB: …so was it less severe than it has become subsequently?

HWM08: Um, that was the most severe episode where I've been admitted. It has got more.. but then obviously after that it seemed to start to calm down on dig [digoxin] initially and then under the cardiologist. So I had a couple of years of calming down. But I also had increased episodes so then

obviously I went to see [Cardiologist A, name], yeah, he did my ablation but he was the one that kind of felt like this would be a good.. that's the start because I was having quite a lot more episodes within that two year period after the initial episode of being admitted, so er, yeah, it was.. so and then I mean because he thought it was the right thing to do. Yeah.

RB: Yeah. What did you think about it?

HWM08: Um, I was really quite happy to, I mean I've got great confidence in him. I think he scared the life out of my husband because he's very.. he absolutely explains absolutely everything, and I thought that was great, you know? My husband is none-medical so he nearly fell off the chair because… "We're going to freeze this bit of your pulmonary vein, we're going do this and this bit" and I was actually quite happy, and I was really happy with the results, for a long time. You know, yeah, for a long time. It was really good. Yeah.

RB: Oh he'd be proud of that

HWM08: Yeah. So, yeah, yeah.

RB: Brill, ok. So um the next part talks about treatments, so have.. were you ever cardioverted or did you just go straight for the ablation?

HWM08: Straight for the ablation. I was never cardioverted, no.

RB: It sounds like you were paroxysmal anyway, so..

HWM08: Yeah, yeah.

RB: Um and over the last year have you had to go into A&E at all with your AF?

HWM08: Um, well about a year ago, June last year so not this year, last year, I did go.. I ended up having a TIA so I had a, a small stroke, er and it was triggered off by my AF, so that's how I ended up in A&E last year. And obviously this time post-surgery I ended up but that's normally no. But I had a, June last year I had a TIA, quite a large one, er which is quite scary. And I think the thing is they had actually taken.. because I don't see [City] every time, I see my own cardiologist here, [name of Cardiologist B] who works for [City], one of the consultants who didn't know me felt that my CHADS score which is the anti-coagulant score was low and I had been really on warfarin and not managing. And they took me off my anticoagulants and I'd been off them for a year, so I'm now straight back, I've obviously been on them for a year again now. So, yeah. So that was my TIA, well quite a small bleed, more than a TIA, triggered off, my AF triggered it off. So that was kind of one of the reasons why I agreed to have another ablation as well, because you know, there's that.. But I'm loaded with anticoagulants now which is fine.

RB: Right. Are you still on warfarin or are you on a NOAC now?

HWM08: No, I'm on another one now, because warfarin, my warfarin levels were just ridiculous. I was having weekly bloods, they were going from like 1.5 to 4 within a week.

RB: Some people are very unstable warfarin aren't they

HWM08: Yeah, so um, I'm on one of the new ones is it.. um, starts with a D

RB: Dabigatran?

HWM08: That's it, I can never say the word. And it's fine, and it's fine, I feel more comfortable. Which if I was having an ablation and hadn't had any anti-coagulants I'd be quite scared, you know?

RB: Yeah, yeah, ok. Um, so in terms of hospitalisation in the past year were you.. you were only hospitalised for your LACA, for your ablation?

HWM08: Yeah, that's it

RB: Oh and then for the pericarditis afterwards

HWM08: Yeah, yeah

RB: And in the last year how many times have you seen a cardiologist?

HWM08: Twice

RB: Twice, uh-huh. And that was your own cardiologist and then [Cardiologist B name] presumably to talk about the ablation?

HWM08: [Cardiologist B] is my own cardiologist anyway..

RB: Ah, ok

HWM08: ..because she's now working for [hospital] as well as [City], so I've seen [Cardiologist B] twice, and then I saw her for the pre-op to the ablation.

RB: Yeah, ok, that's fine. So now we're going to talk a little bit more about the symptoms and the types of symptoms, so have you.. do you have palpitations at all?

HWM08: Yes, I do, yeah

RB: And how much does that bother you?

HWM08: Um it can.. it bothers me in that I get quite short of breath and um, sorry, the dog's just come in, sorry

RB: That's alright!

HWM08: But my husband has brought me coffee so I can't complain. It does make me short of breath and it bothers me from the point of view of um, walking, you know with my husband, um, I'm not very good, I'm not fit, which I know, but liking, my husband walks quite a long way with the dogs and I have to stop and things like that so that kind of is quite frustrating, and a bit embarrassing, very embarrassing, yeah. So.. Things like that and maybe sometimes at work, in the obviously like any hospital long corridors and stuff and, er, it's the walking and exertion that takes my breath away and I'm.. the AF, it's the AF is triggered off, yeah, yeah..

RB: How far can you walk?

HWM08: Um, cor I don't know.. without stopping, maybe half a mile.. but, you know, on a good day. On a bad day, not very many steps. Um, I try and do ten thousand steps a day which doesn't always work out, so sometimes, if I do it in steps about eleven hundred steps and I have to stop..

RB: Right

HWM08: ..Yeah, and sometimes it's less. So it's one of the things that is.. bothers me.

RB: Yeah, Yeah, ok

HWM08: I've got a little grandson of four and I've got twins coming so to be able to … and a lot that I know the reason's not just the AF, it's obviously that I'm clinically obese so that doesn't, doesn't obviously help at all.

RB: It's a combination though isn't it though and what I'm interested in with this study is how those things work together

HWM08: Yeah, yeah, it is and it is that when I'm less.. when, when I lost weight, saying I haven't lost weigh this year but two years ago my daughter got married so I lost about three stone and that made me feel better and also when I say the episodes of AF have reduced, I think so, yeah. Because I don't know, but I think so, yeah. Because you also like to not think that, because everyone who's overweight, especially people like me are always in denial til you look at the photographs [laughing sadly] and realise you look awful. So. Yeah.

RB: Ok. So you obviously have a lot of shortness of breath when you're walking about – do you get shortness of breath when you're at rest?

HWM08: Can do but not as much as walking about. And, you know, I can go short of breath, it suddenly comes on and it's very difficult to sort of gauge especially this past couple of weeks because that was one of the symptoms of the pericarditis I had it, within 24 hours of having the ablation, um, really really short of breath. But I think that was just because of the inflammation rather than anything else, so um, it's kind of hard to um gauge it but I have had shortness of breath when I'm watching the TV or reading a book or something, but more so when I'm at work, when I'm going about my work and lifestyle you know, my daily life really.

RB: Yeah, ok. And do you ever get light headed or dizzy?

HWM08: Yes. That's one of the things as I say you can get, the one that makes me feel.. the yeucky feeling you know, you're really out of control it's that kind of lightheadedness and dizziness, you feel you're going to fall on the floor. And I mean I always say, you know they always say when you're going is your blood pressure ok, my blood pressure's always quite low but that's normal for me, so that's um… And also you know that my pulse is quite low, I do run at a pulse rate of 40, 45. Which is obviously… always get very excited so I always say oh well I'm not a sportsman, I'm induced, I'm drug induced. And I'm having an episode so yeah. Yeah yeah, so yeah.

RB: And does it make you feel tired?

HWM08: Yeah, can do, yeah, yeah. Especially when you've had like quite a few episodes within a short period of time. And also if you, you know if you get shortness of breath and you've been walking and yeah, you do feel quite tired.

RB: Yeah. And then do you ever get any chest pain or pressure?

HWM08: Central chest pain sometimes, and er, but you say but you can tell it's that kind of pain rather than people going "oh my god!"…

RB: [laughing] you don't think you're having a heart attack

HWM08: …and "it's a heart attack", I'm *not* having one of those, yeah. It's er, like a thump in your chest do you know what I mean? It's kind of like a.. yeah, yeah.. but it goes very quickly, yeah.

RB: Yeah, ok. That's the end of that first questionnaire. So the second one is called the EQ-5D-5L so you might be familiar with this if you've done any research ever in your life

HWM08: Ok yeah

RB: And this is the one.. there are five questions about mobility, self-care, usual activities, pain and discomfort, anxiety and depression and then we ask you to give yourself a score

HWM08: Ok

RB: So the first question is about mobility, and it's I have no problems in walking about, I have slight problems in walking about, I have moderate problems in walking about, I have severe problems in walking about, or I am unable to walk about.

HWM08: I'd say the moderately, rather than I could say slightly, but I'd say moderately if I was being perfectly honest.

RB: And then what about self-care? And this talks about washing and dressing yourself?

HWM08: Self-care there's no problem

RB: Then usual activities such as work, housework, family or leisure activities

HWM08: Um, I would say I do them all but um.. sometimes obviously limited running after a four-year-old or after a dog or something so I don't know, I'd say slight, rather than moderately. I can do them all but I'd like to do them better

RB: Yeah, ok. Is there anything that you would like to do that you feel you really can't do?

HWM08: Um, I'd like to walk fast or possibly run or ride a bike again. It sounds silly but those things as .. my retirement, my husband and I's retirement we'd like to walk the coastal paths, my husband's Welsh from [place name] so.. we've got a caravan. You know things to increase my activities, to be able to enjoy my life a little bit more.

RB: Yeah. Yeah, ok. Do you have any pain or discomfort?

HWM08: Um no, just only on those episodes when they come but otherwise it's not a long term sort of thing, no.

RB: Um and then about mood, do you have any anxiety or depression?

HWM08: Um, I do yeah, I get quite a.. I'm quite an anxious person. Um, mainly about life itself at the moment I suppose you could say that about everybody this year but um

RB: Yeah it's a bit of a peculiar time to be doing this study actually because it's quite affected [by COVID]

HWM08: Yeah, I do, I like to be in control so anxiety about getting, being and um I worry about everybody and my family and about doing a good job at work, about all the things I am quite an anxious person. And I don't rel.. I'm not good at relaxing or laid back kind of person, not at all. Except at work which is completely different to at home. Much calmer at work than I am at home [laughing]. Because I know what I'm doing at work whereas at home it's a bit different, so.. and we are in the middle of a sandwich if you know what I mean, we've got elderly parents so, families and that so.. very much [inaudible]. But that's us, that's me, I like to be in control

RB: You like to be in control, yes. So then, we've got this sort of thermometer on the back from zero being the worst health you can imagine to 100 being the best health you can imagine, what score would you give yourself on that scale?

HWM08: Fifty. And that's not just because I'm going straight in the middle, I just think it's out there either way. Fifty to sixty I'd say. Yeah, lots of things I could improve on to make myself healthier, so um..

RB: Well let's talk about some of those things, what would you say those things are?

HWM08: Er weight, overweight is the big said she, I've got the most awful eating habits and addiction to ridiculously rubbishy things. I can't stick to a diet and I have a degree in weight-watchers and I do quite well for maybe a short period of time but I can't sustain it and I'm and there's lots of, you know, the thing that's frustrating me is I know all the reasons why and I know all the reasons, the pre-disposing factors. I don't know, there's something blocking me, mentally or, don't know, but my brains not wired so it's not um physical issues I don't think so much as psychological issues. And it's the psychological issues because you can reel off what you should eat it's just the psychological part of me that I can't overcome

RB: Sure so you know what you need to do to lose weight – and you, you have lost weight in the past obviously because..

HWM08: Yeah I have I have. I have, I have. Um, in my twenties I was not that.. I mean I'm only five-foot-three, so someone being only 5'3 and over a hundred kilos is not, obviously… so my BMI has always been about 30, you know, and when I was in my late twen.. my late thirties.. But in my early teens I was also overweight and I made a conscious effort to you know, even having children, but I don't know what happened it sort of spirals and spirals and spirals and spirals. And um obviously contributing factors of having AF, I think it obviously contributed to me having AF, that's my idea I don't know if it's true, and obviously things just got spiralled out of control and you know you don't

look in mirrors and you do all the things you don't do, like people who like me don't. And it worries me because my children are absolutely fitness - you know, grown up children of thirty, thirty-two – fitness freaks and diet freaks and I worry that – they're not freaks, my children are not freaks [laughing] – they're very good at maintaining..

RB: (laughing) they're very keen on those things

HWM08: ..yeah. And I, that's kind of sad for me, really. I mean it's good for them, but sad for me. Yeah.

RB: Why does it make you feel sad?

HWM08: Well uh, just thinking whether they, they are very, my son particularly has a bit of OCD, and they are very obsessed with making sure they eat like healthily and that's just *right*, but they are slightly obsess.. obsessive practice as well. And I just wonder whether it's psychologically triggered by looking at their mum. Yeah. Yeah. So um.. But you know I have done some things I've done really well but I never sustain it, it seems to you know.. have like a year or so when I'm not perfect but better than I am now, then I go back to.. And this year I'm using the excuse like everybody else [COVID-19] but my year of COVID was before that, you know everyone else is going "Oh yes you've put on a few pounds" and I'm "Oh yes, yes I have". And I'm, and the year before that, and before that, but you go on the bandwagon with everyone else because it sounds better and it makes you feel better but it doesn't because it obviously doesn't.. but you know. Ahh! It's like confession time here [both laugh]. Sorry nursing guilt and a catholic and a fat person, and oh god it's not a good combination. But er…

RB: So going back to the connection between overweight and AF, you said that you were, that you believe it may have been a trigger for you but you weren't particularly aware that there is a connection

HWM08: No, not at all, no.

RB: What sort of advice have you had over the years from doctors about managing your weight and later on from cardiologists if any?

HWM08: Um, minimal. Minimal. Obviously I had a.. Obviously there is heart disease in my family and my father died when I was 22 suddenly at this time, at 49, all those years ago. And he was a smoker so I mean you always hear about, he was a smoker and had heart disease, and he was quite a thin chap. But there was always like a there was never any particularly mentioned about weight until this year. Um, about a month before I was down to do my have my ablation when [Cardiologist B] rang me. And um, because I know [Cardiologist B] obviously from work and know her well. And obviously I'd put on a good couple of kilos this year compared to last year's, um, appointment. She's the first person that has actually said from a cardiology point of view about the risks of the ablation, you know, going ahead with the ablation well I thought it was a good idea. Try and lose some weight, well I did lose of couple of.. because they called me really quickly so.. I got those it would be a good idea to lose, lose some weight, a) for the effectiveness of the ablation and also for the risk factors. But that's the first cardiologist that has had that conversation with me. And that was a good conversation. Quite a scary one but a good one in that respect because no-one's actually said AF and weight – that's the first. And also that's the first time I've ever actually had that proper conversation

about it so you know. But it was quite a good, well, absolutely right conversation to have. But otherwise you just have a few mutterings. GPs, I find my GP um, they don't want to talk about AF, they just leave it to other people.

RB: Right.

HWM08: Because I had a run of AF maybe at the beginning of the lockdown and I didn't want to go to A&E and I didn't want to go to my hospital because I knew that we were in lockdown and he asked if I could come "can you pop in and have an ECG at your own place" when it's, we can't do it you know, there's not a lot we can do. So. Which doesn't help. Because you're trying not to go to A&E and also not to bother a cardiologist with a simple ECG that someone could read. Um, and I've never had a conversation with my GP about, um, AF and weight. Not at all. They very rarely talk about AF to me.

RB: Sure. Do you think that's because they don't feel they have the knowledge?

HWM08: Yeah I think so, they think oh well you're under the hospital and you work there..

RB: Sort yourself out.

HWM08: Yeah, yeah basically. Get on with it. So yeah.

RB: And what about the weight, has your GP ever spoken to you about your weight?

HWM08: Um, yes. Um, a couple, a good couple of years ago now I did go and see, well I was supposed to be on a waiting list for a weight psychological help. But the service was pulled here. So there were… sorry that's my Doberman, he can open doors, he opens doors, he's too clever. You can't come in here. He opens all the doors. And cupboards. And the oven.

RB: Really?

HWM08: Yeah, we have, you know childlocks – we had childlocks on cupboards before we ever had children. Because [dog name] can open all the doors and all the tins, you know

RB: Oh they're so funny aren't they, they just make you laugh.

HWM08: Too clever, much too clever. We've had, spaniels are really thick. I think Dobermans are too clever.

RB: So going back to when you lost weight for your daughter's wedding, what was different for you then psychologically, and how did you go about losing that weight?

HWM08 I think it's because it was just a really big event in my life, you know and I wanted to be, um, not show her up. You know? And I think I did just normal things that I do anyway, really, joined Weight Watchers and going and doing a bit more exercise, and as I lost a bit of weight the AF didn't come on as much. So I was able to do.. because I felt well. You know, felt really well. And then everything kind of, well for at least a year afterwards. And then you go into your real bad habits again and lifestyles change and, I can't remember. There was no excuse, I can't think of an excuse, there isn't an excuse to think about so .. I don't know it's kind of like something outside like lightbulb moments go, candle's burnt out and you go down the wrong route again.

RB Yeah so do you see.. it was kind of a temporary thing that you had maybe, the wedding as an objective..

HWM08 It was, yeah, yeah. And then I did try and lose weight after, because one of the things that did scare the life out of me is having a stroke. And I was I had actually started doing well again, and then this year's been a bit of a, kind of year. Um and then you don't.. and then you have increased AF and stuff so your not walking and not, you know my husband walks all the time and I feel quite, you know he walks three or four miles a days and all things that he likes to, he has his, we live in a village, there's quite a big farm and they all walk, and they walk very quickly a lot of his friends and I think I'd quite like to be like that so then you don't do it because you feel like embarrassed so you end up not doing any exercise which is not a good idea either so..

RB: Do you feel like it's almost a bit of a vicious cycle then?

HWM08: Yeah it is, and it's.. and you know, and you want to feel well but you know, and um, but you don't want to be the one that's the fat grandma at the school, I don't like being the fat grandma at school, because kids.. you don't want to show them up. So again we're off, 2021 again we're off from January the 1st you know we'll try, we'll try again. So I have tried to do a little bit of walking, I have got better actually, just a week or so I wasn't very well after my pericarditis so couldn't really [speaks to dog] no, sorry um out, sorry, we back onto the back of a farm so he's watching all the people walking along with their dogs, he can see them all, he can spot all the dogs that are out and if any of them are friends "Oh there they are!"

RB: Go and bark at them urgently [both laugh]

HWM08: Yeah, we've got little shopping robots here..

RB: Oh wow!

HWM08: ..which is one of the first parts of the country that does shopping deliveries with robots, from the local shop, so we've got little pods that come up and down the street that deliver shopping you can order it on an app. So the dogs, all of them in this village are going bloody mad, barking at all the bloody robots going up and down the road.

RB: That's amazing I hadn't heard about that!

HWM08: It's very clever, my little grandson thinks it's great fun, but I don't think that people with dogs are all that pleased because the dogs all "grrr". It's alright I've got [dog name], I keep stroking his ears, he's fine

RB: Aw! Comforting. So, um, thinking about exercise and AF, do you feel like your AF holds you back from losing weight because of your exercise capacity at all?

HWM08: Um, I don't think it is. I think for me it's a psychological.. me, um, shoving too much rubbish in my mouth rather than the exercise. Because if I'd felt well and lost weight then I'd exercise more and my AF would be more controlled. So, er, so I think it's, it's me I, I feel like when I have lost weight in the past I shift, if I just shift a stone, then I actually feel better to be able to exercise. Because if you try and do it like, I put it as if I'm shoving up a hill with a whole full load, give me half a load and you get it up the hill quicker. You know, so and I think mine is the psychological and the

physically rubbish I put in my mouth causing me to phys.. causing me to put on weight then not being able to exercise. But in the past when I've lost weight, even though it's a stone, you feel like you can do exercise more so no my AF isn't causing me.. it can still trigger off of exercise but it isn't causing me as much grief of trying to push things up a hill that you can't, you know, can't get there so..

RB: Yeah. Do you feel that if you were out walking or anything, like if you said to yourself right I'm going to go out for a big walk, would you feel safe doing that you know knowing that you get dizzy and so on?

HWM08: Yeah, I would do, I mean we always well we tend.. We're quite luck y where we live so I do try and.. we were walking in the morning, obviously it's a bit dark at the moment so I can walk, I do try and walk on my own if I can, I do feel safe, so yeah, I don't think.. I mean I might have to stop, but that's fine, I'll recover and go ahead. As I feel like, no, even if I have to stop it's better than doing nothing, so yeah..

RB: That's interesting because a lot of other participants in this have said that they don't feel safe because of.. they can feel things happening to their heart. Do you think your nursing knowledge helps you rationalise it?

HWM08: Yeah I think it does, so yeah, yeah, yeah. Yeah, we're a bit of a funny breed us nurses, I think we tend to.. ok, carry on it's fine, it's fine. I'll just take a breath and I'll go ahead. I think it is, I think it is. Well either one way or the other, you know, if it's my family I'm decided.. no child of mine's ever had just a normal headache, they've always had meningitis or whatever it is you think, yeah. They've got a temperature they definitely, not COVID but you know the normal stuff. Or if he's got a slight pain in his arm "Where've you got pain from?". But me, you think oh it's fine, take a breath and I'll be alright. I think it is nursing knowledge, I think it is, it's kind of er…

RB: You mentioned that you were hoping to have some psychological help regarding your eating but that programme was cancelled

HWM08: Yeah

RB: Um, can you tell me a little bit about that?

HWM08: I think it's a kind of, it's a psychological, I think it's having, understanding how I can't sustain things, you know, and actually it's to be honest it's like the comfort eating is a lot to do with anxiety, you know, for me, it's comfort food, anxiety or the combination of things and then you put on weight so you then go into this, so it's kind of trying to break that cycle of why are you having to comfort eat, why do you get that.. I don't know, whatever the right word to say is, that kick out of eating one thing that you know is wrong, but you have that sudden buzz of.. you've eaten something that you quite like. And then the anxiety is.. so the anxiety triggers off the comfort eating or the other way and then the guilt and the weight that goes on with that, you know all the combination. I think those were things that we were talking about when I spoke to my GP which is a long time ago now. You join a diet club, you know you do whatever it is, you do it online, you do Joe Wicks or whatever it is, that's fine, but that's not the bit for me. That, there's the exercise and the diet which you know are the two things that will lose weight, but that's not the, that's not.. those two things aren't the things that trigger me, it's another bit to that puzzle which I'd love to know, if I was

honest. I can't quite, you know.. And I, whether it's discipline or whether. .I don't know.. and you also feel self-loathing, that's the other bit of that, the self-loathing of being fat. And you learn not to look in mirrors, you learn not to.. You learn to buy lots of handbags and shoes, that's what you tend to do if you're fat. I've got lots of very nice handbags and shoes. And scarves. Those are the things if you go shopping. So if you're going, I have some, I have a really lovely friend whose poorly, but obviously love to go shopping, we've been shopping across the world, places like Boston, Canada and all sorts of um.. very skinny lovely looking lady so you're always looking at her, whatever lovely shops and I'm "I'll just go and look at the shoes, the handbags" [talks to dog] Out! Sorry. Sorry. Get out, go and bark outside. Let me just pull my curtains bear with me because he's getting very.. people are going up our path to church. They've gone now [dog name], they've gone. So I would say that psychological element that I don't understand would be one of my other factors

RB: ..Would be what you've got to get to the bottom of. Just, I was interested in what you said about the handbags and the shoes – is that because you don't want to admit your dress size or is that because you want to sort of decorate yourself?

HWM08: Yes yes yes and also you don't want to admit your dress size and you also know that you can't, you also know it's that very guilty thing about.. sorry I'm just shutting the door on [dog name].. you don't want to admit that you actually can't buy anything in this shop, there's nothing for you. People have, you know.. whereas I know some of the shops and the very designer shops don't do anything above a size 8 anyway but like I don't mean, we're talking about very large sizes and you know that if you go to a shop you always go to the back, you always look at things at.. you never look at the front of this array of clothes, you've got to see [whispers] "Have they got my size?" before I even start, so you know, um. So you don't.. you know things like.. I don't know, whoever it is they don't do above a 12 anyway so.. oh they do nice shoes. I've got seven.. we always have a friend whose quite large but not as large as me, so it's actually.. so at least I only need size six shoes, rather than size six dress size [both laugh]

RB: How does that make you feel? I'll tell you something that happened to me years and years ago I was trying to get a dress to go to my brother's wedding and I went to a shop in the covered market in [City]. Now I'm a size 10, and I went into this shop and this shop assistant who I think was a dress size bigger than me said "Oh I'm sorry we don't have anything for women your size in this shop"..

HWM08: Yeah it is

RB: I felt really furious, I felt.. not insulted personally because I don't care, I mean, I think my body is ok, but on behalf of everybody really that they wouldn't cater for anybody who was above a stick size

HWM08: Yeah it is I mean, obviously someone like me you don't expect people to cater for, um, but you do, you feel quite shameful, it quite a.. you feel quite shameful, quite embarrassed and shameful. I sometimes get angry but it's not.. you're angry with yourself rather than with the, you know, and I have a friend who's like you, very good body shape, and she's had that and I'll be angry for her, I'll be angry for you, but I wouldn't be angry for me, you know so.. because actually well it's all your own fault anyway. You know, that's um.. it's like people that smoke, who've had heart attacks and stuff or women who are pregnant and smoke, I get quite angry about that, but you think, you know look at yourself in a mirror first.. it's always all that kind of.. because I've put down being

overweight as self-harm, you know it is an addiction. People never associate weight with an addiction, you know if I was a drug deal.. a drug addict or a smoker, anti-smoking we've got lots of anti-smoking things, you know, even at work when people can't have their e-cigarettes, they're poorly, we put patches on them and stuff like that, but does anyone offer support for someone whose addicted to food? No. And you know, so..

RB: That's really interesting

HWM08: And I would say it's a self-harm. You know, and I can say that blatantly, because it is. But if I was.. had mental health problems and I was.. an eating disorder the other way, people would associate that. Or I had problems getting off drugs or drink or whatever, there's programmes for that. But there isn't anything when people are eating, you know people who have that real difficulty, um, and it's all very well to say how simple it is- is it? I don't think it is simple, because if it is simple the very large diet companies are making a hell of a lot of money out of people who are.. But I do think people like me, it's that.. and that's not an excuse it, it's still that there are those factors that you have to lose weight with exercise, yes you do, yeah so it's yeah, but I've always said that and I've thought it more and more, but no-one's ever said.. no-one's offered it, they've all just kind of said "Here you go, there's a diet sheet, off you go". Whereas if it's a drug dealer, a drug addict or someone on ETOH, we'd have a detox programme, or um..

RB: Yeah, that's really interesting

HWM08: That's my theory anyway. Probably complete rubbish

RB: Yeah, it's interesting because you hear this really flippant oh, eat less move more sort of thing, but nobody ever says to an alcoholic "just don't go to the offy"

HWM08: Yeah, they don't, they say what help and support would you like, well, we know there's great difficulty with all services anyway but there is that kind of thing, you know like if I came into hospital and I was detoxing you know physically it would affect me, but actually no-one would actually, oh with weight oh you need to lose weight – well don't stand over my bed and say that because actually I know that, so that doesn't help me, it doesn't you know, shaming me into losing weight it can do. You know, physically having a stroke last year frightened me, um, pericarditis um but [Cardiologist B] said that's got nothing to do with the weight, just one of those unfortunate things, um. But it still frightened me because I thought I've done this bad th.. I've had this ablation and that's because I didn't lose all the weight I was supposed to have lost. But when I came into Oxford no-one said that to me, it was only [Cardiologist B], they were oh you're fine yeah no worries, no problem. And you think ok, and then I was feeling unwell the day aft.. the night after I had my op when I felt really unwell like sort of god there's something dodgy going on here – I felt really guilty, you know, really guilty. 'Cause um, yeah, so it's.. but if I was an alcoholic, have a last drink, one last drink, but there isn't a support.. don't think there is, maybe I'm not looking in the right direction, but, from the NHS point of view there isn't, there isn't anything. And associated with AF, as I said the first person that's ever really spoken to me about losing weight due to my AF is [Cardiologist B], this year.

RB: Yeah.. So it sounds like, I mean in terms of, as I said at the beginning I'm interested in what sort of services people would like to see, that sounds like.. do you think like.. some sort of cognitive behavioural therapy, something like that would be beneficial?

HWM08: Yeah, I do, yeah. Yeah and I think everybody's.. you know, one size won't fit all anyway but I think there's a combination of the other two things, the physical aspect of losing weight, but I do think that bit hasn't been addressed. I , I might as I say I might be completely wrong and it's just me but I can.. as I said I can give.. I've got a degree in diets and um my bank balance tells me something completely different, and I, I enjoy when you do physically lose some weight, you do get that funny.. you know that euphoria, those endorphins which you know you get. But I also get endorphins from eating rubbish. You know? Don't know. Maybe I'm just wired wrong. Something like that – I'm doing completely rubbish anyway…!

RB: Do you think it's to do with like a quicker gratification from eating something?

HWM08: Yes, yes, definitely.

RB: It's like an instant feeling rather than having to get your trainers on and go out for a walk, and wait months to see the results…

HWM08: Yeah, yeah, and I've been a member of a gym and I've done quite a lot of gym work, well obviously I'm a bit older now but maybe ten years ago maybe less well longer than that and I loved that feeling of using the cross-trainer so it's not as if I haven't [inaudible] which is even more frustrating. Sorry the dog is.. You're being a pain [dog name], go and sit and be quiet. Sorry. It's quite interesting. [To dog] you're not fat, you're thin and beautiful and lean – damn dog! [laughing]. Yeah.

[Pause]

HWM08: Are you ok?

RB: Pardon?

HWM08: Are you ok there? Sorry I'm just walking across the room to keep [dog name] quiet, sorry.

RB: No that's alright, I'm just glad it's your dog being a nuisance and not mine for once!

HWM08: He's falling asleep now, he's had enough now. [Both laugh]

RB: I think that's more or less everything that I wanted to talk about, so we've talked about um.. your AF and the connection with your weight, and you obviously have.. physically you have the opportunities to lose weight, you know what you need to do in terms of eating and exercise and you're able to get out for exercise. But then you sort of, it sounds like you sort of break down and comfort eat as you were saying, yeah, and that psychologically it would be useful to have some support to try and find the mechanism behind that..

HWM08: Absolutely, I think that's um.. I don't think in my lifetime there'll ever be a kind of service that would offer that but I think, you know, somebody might think about the psychological aspects of people who are overweight, um, clinically obese, I don't mean someone whose got half a stone to lose, I mean . I think you've hit the nail on the head, that gratification of one second in the mouth

which you can get from opening a packet of sweets compared to walking round the block. And I think that's.. you know, that's kind of like..

RB: That's what happens..

HWM08: Yeah, yeah. And it's really awful because you do feel crap at the same time. Don't put that in your data! Don't use that word crap, that woman said crap!

RB: That's going in my title now!

HWM08: Handbags and shoes first!

RB: Well you know, you want an attention-grabbing headline don't you?

HWM08: Yeah, yeah, you do.

RB: Can I ask you one other thing – has anybody ever talked to you about, or what's your opinion of gastric banding?

HWM08: Yeah, um, no. Never. My husband has, from a physi.. um, I've always been quite frightened of it, um, and I've nursed – my background besides safeguarding is Intensive Care, and I nursed somebody a long.. I mean obviously years ago who had a gastric band that went wrong. So I was always a bit um.. But my husband, because I think he's obviously gone through – I mean he's extremely supportive, don't get me wrong at all – but obviously he watches me and watches me.. cry and things like that, because you do, you don't just keep it all, you do have your bad spots.. he's the only person who has ever said, and nobody else has ever asked anything. I mean I've looked into and we've looked into it but I don't, rr-rr, quite scary. And I want to be able to be.. I don't know, I want my cake and I want to be able to eat it – I definitely want cake! Um , I want to be able to have the normal lifestyle as well, whereas obviously things like gastric bands don't have that. I mean I've done all sorts of weird diets, Cambridge diet, all sorts of things, which er only in the short term, but er yeah we're doing and my husband's the only person who has ever mentioned it to me. I mean as an act.. as a very very supportive as a husband rather than because he wants his wife who he's known, what is it 34 years? To you know, be a different person. Yeah. That's the only thing I get wrong. Well, it's one of the biggest things I mean that I get wrong. So er, so you know er that's why going to work is a good thing. Because I'm hopefully good at my job. Retiring's quite hard. You then lose.. you lose your own independence. You lose your own identity and respect, to become the wife of the husband who's got the Doberman – that's one of the ones in the village anyway- and who doesn't always walk the same as him. So that's kind of hard. Yeah. But things will change. Because I've got blimmin' twins coming along, I think I'll be jogging for England as well as everything else.

RB: Absolutely! Do you think you'll be able to .. I mean once.. hopefully this ablation will settle things down for you with your AF, do you think you'll be able to physically do more?

HWM08: I hope so. I do. I do hope so. Yeah, and that's one of the reasons I agreed to have the ablation. A) because of having the stroke last year which frightened me, and from the point of view of having these runs of AF, um, not being as physically well. And yeah. That would be my aim. Well, that would be my biggest aim, even compared to coming off medication. That would be my aim, that would be.. that would be the thing I want for 2021

RB: Sure. So if you could feel physically well but stay on the medication you'd be happy with that?

HWM08: Er yeah. But if I could come off both…

RB: Would be the ultimate

HWM08: That would be the ultimate.

RB: You'd rather be on medication and feeling well, than off medication and not feeling well.

HWM08: Yeah. Yeah. But I do feel much better from a.. do you know just that.. I do feel that the past two weeks I've felt much better in my AF, had no runs at all or anything. I know I'm still on my tablets but actually I do feel better. Um. The pericarditis wasn't particularly nice um.. but yeah it's two weeks tom.. it's two weeks, two weeks exactly [inaudible]

RB: Just one other thing, sorry, before we sort of wrap up, um, if a service were available, like a cognitive behaviour therapy service but not through the NHS, is it something that you would be in a position to pay for…

HWM08: Yes. We would be.

RB: … or would that be a limitation for you as well?

HWM08: We would be financially able to do it. I've looked, um , at times, in the past, and then you think.. oh they're all wacky [both laugh] oh. Er my daughter has been.. my daughter has other problems, physical stuff which is caused by.. She's been to see a psychologist I knew from my old days. But I know him, he's a really good guy. But I obviously wouldn't want to use somebody I know. Er, no definitely not. No, she has autoimmune disease which she got er, when she had my grandson. And she again is a person that likes to be in control . And when it's like, like post-traumatic stress syndrome where this world has.. where her world has changed, and this guy has worked really well with her. So I think somebody like this, similar or something, if there was somebody who specifically, not some kind of whacky, do you know what I mean, lay your hands and sniff lavender oil and you'll be fine kind of person, rather than somebody who has actually done a study of it. I'd rather they, they need to know what they're doing. You need to know what the issues are, rather than oh it's just somebody else who just wants to lose weight – actually it's not that, well it is that, but it's something else as well. So um yeah, but we would.. I have looked at it in the past, I couldn't see anyone in particular.

RB: I don't have any recommendations, sorry, I'm just interested…

HWM08: No, No I have looked at it, we have looked at it. I mean obviously from our point of view we're quite lucky so we could afford it, um, can't find anyone particular. No, no.

RB: Sure. That's really all my questions [name] thank you so much for talking to me. Is there anything else that you wanted to bring up..?

HWM08: No , no, just um just let me know when you publish your da.. your um research, and good luck with your masters. And I'm sorry I've been really honest which is..has made me feel..

[embarrassed laugh] I've actually never spoken to anybody about it so I don't know you but thank you very much for listening to me babbling on..

RB: No it's been wonderful, I mean from my point of view I'm delighted when people do that obviously, because I'm I'm trying to do qualitative interviews here so it's exactly what I need. Um, what I'll do as I said is I'll produce a summary and I'll email it to you for you to look through and just see if I've kind of got the gist right of what you're saying.

HWM08: Yeah that's lovely that's great that's fine yeah.

RB: If there are any bits you want me to edit I will do. Sorry my husband's at the door, he'll probably just.. bear with me a minute

HWM08: Yeah the doberman's just er says goodbye, he's bored with everybody so he's gone to sleep. So he's like he's not worried about diet, he's just eaten a load of vitamin D tablets this morning as well, so just er..

RB: Just one other technical question before I go – I haven't decided whether I'm going to use numbers or pseudonyms for the reporting of the study. If I were to use a pseudonym for you, what would you like to be called?

HWM08: Um, Handbag60, does that sound a bit..? Or Retire-at-60, which was one of my comment.. Handbag60. Is that a bit weird?

RB: Well most people have chosen a name….

HWM08: I'll choose a name then, I'll choose a name. Um. SOVA60.

RB: Ok.

HWM08: So that's short for Safeguarding and 60 is my age. So.

RB: Ok, no problem

HWM08: Or SOVA, just Sova if you like. So [discussion about work password not transcribed for security reasons]. It was very exciting before COVID came I was retiring in April but as we went into lockdown my retirement came and went. It's not a good time to retire when COVID comes anyway

RB: It's not a good time to do anything is it?

HWM08: No I know I'm going to have the vaccine, I'm getting the vaccine tomorrow actually.

RB: Oh brilliant!

HWM08: Because we're one of the hubs – I mean I'm sure it's the same – we're one of the hubs and we're going to vaccinate people after Chr.. We're doing the mass vaccinations, we volunteered to do the vaccinations, so yeah. So um, might as well have it 'cause then.. Yeah, try and look at these cynical people who are on Sky News and have you got any severe allergies and all that sort of thing. Let's get it out there.

RB: Yeah, I work on two of the vaccine studies as well actually, at the hospital

HWM08: Oh have you? Oh yeah, of course

RB: Yeah ‘cause we’ve all been, ‘cause I work in cardiac research as my day job, and we’ve all been redeployed first to clinical areas and then to vaccine studies

HWM08: Yeah, yeah, our research nurses here as well, but not as much as obviously not as much as [City]. So when’s your one due, is it coming?

RB: I don’t know because they’ve had to re-analyse all the data because they had that funny thing happen in Brazil with this smaller dose being more effective. So I’m not sure what they’re doing with that now and it seems like when they’ve re-analysed it they’re at about 60% efficiency. So I think they’re having to decide whether to re-trial with the smaller dose. Because the smaller group who had a smaller dose have had a better reaction, but that’s enough people to say whether it’s a true effect or not or whether it’s just chance, that they’ve had that finding, statistically.

HWM08: Oh ok. Well hopefully…

RB: Yeah, I mean, I’m sure they will role it out but I mean apart fro anything it’s so much cheaper than all the others.

HWM08: Well yes, there’s always a cost implication! Ok yeah, well thanks very much. I’ll say merry Christmas and hope you have a good one. Ok thank you.

RB: Thank you and all the best with all your grandchildren, and I’ll be in touch with the summary soon.

HWM08: Ok, thank you very much indeed.

[ENDS]