

Fit for Future

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SI: So first of all, to introduce myself to the very few people here who don't already know me. I'm Simone Illger and I'm Chair of the NAC's Health and Wellbeing Committee. I'm going to do the slides now Roland. Thank you for your help.

Before I put the first slide on, if you're of a nervous disposition, please look away. But I just want to remind you why I feel I'm qualified to try and sell the idea of Fit for the Future for you and the fact that you should, but for your own sake lose weight and try to move a bit more ... I'll get rid of that picture ...

F1: Question asked from the floor by visually impaired participant asking Simone to describe the picture.

SI: Oh, sorry. Sorry. It's a picture of me when I was probably about four and a half stone heavier and a picture of me as I was a year ago in my bikini so sorry you're missing out. I'm about a stone heavier than I was this time last year but I'm working on it.

So the next picture is of a sloth snoring gently on the grass. Who can identify with that picture? Right. So let's do something about that, shall we, for those people who are feeling a bit sleepy and a bit sloth-like and I can assure you I'm not going to get you to run around the block or anything. So as you heard from Mark earlier on ... and it was great to ... I didn't plan my talk alongside his but it's almost like I did. These are some things you can do whilst you're sat here.

Do some big shoulder rolls, obviously not if it's going to do any damage to your body, but forwards or backwards. Just sit up straight, we've been sat here all day. Go forward and again. And the other picture is just side neck movements, side to side, you've been staring at the front all day. Who thinks that feels great? Who wishes that they did that on a regular basis? Because it does just sort of revive you a little bit.

Okay. So for those of you that are friends of mine on Facebook, you know I like my recipes don't you? And I like to share my recipes. So I thought I would share one of my recipes with you if you'd like me to.

So it's a recipe for a revitalised thalidomider body. And it's quite a simple recipe. You need some ingredients. The first one is one achy despondent thalidomider. Oh!, There's that sloth again. You need an accessible and relaxing environment, you need 32 enthusiastic participants, you need four interactive and informative workshops, six knowledgeable experts, one swimming pool session and here's what you do.

First of all you ensure that the achy and despondent thalidomider is keen to participate and registers interest in the event on the booking form.

The method: you add the achy despondent thalidomider to the accessible and relaxing environment with the other participants. You stir together gently. Add the knowledgeable experts one at a time, continuing to stir to ensure all the ingredients are mixed and then whisk briskly until slightly invigorated.

Divide the ingredients between the four interactive workshops and continue to stir gently to achieve a smooth consistency removing any major concerns or lumps. Allow the mixture to rest for an hour. Add the remaining workshops and whisk to a frenzy; you can use your electric whisk at this point. We want a nice froth.

Place all the ingredients into the swimming pool session and allow all pain to dissolve. At this point you may want to add a sprinkling of laughter and a dry towel or two and I think we've got something called noodles that you add in, but they're not the type that you eat.

Remove the ingredients and rinse thoroughly before cooking at 21 degrees until nicely risen. Allow to relax overnight. Finish off with a final stir, adding lots of praise, a good dollop of positivity and plenty of knowledge. On-going mutual support will ensure that this recipe is an all-round success. Make sure you share the recipe with all your thalidomider friends.

And that is what Fit for the Future is about. My next slide is a little sloth going "Yeah!" An invigorated sloth.

So before I tell you any more about Fit for the Future, I'm going to tell you about the Swedish exercise programme that you heard about earlier on. I just want to remind people that "They had a dream." Daphne White / Allen, I'm not sure how she likes to be known, but it's either / or, had an idea probably about seven years ago to have this event. She was joined by Susan Kent who's well known for her enthusiasm and Liz Buckle who also joined in and talked and talked and planned this event and here we are seven years later and I think it's going to happen!

The difficulty is, in the meantime, the Swedish have bloomin' overtaken us, they planned their event, held their event and are now sharing the results. So I'm just going to tell you a little bit about that. But of course the good thing is, we can look at what they did and we can make ours better.

So the Swedish exercise project they called Wellness for Body and Soul: A Lifestyle Course for People with Multiple Limb Disabilities and theirs didn't just involve thalidomiders although it was mainly thalidomiders. It involved people with other limb differences. It was a three year joint project organised by four organisations and it was funded by the Swedish Inheritance Fund. It was a lifestyle course in three stages over the course of a year in three different areas of Sweden with between eleven and fifteen different participants attending each event.

Why did they hold this? Well, for the same reasons that we want to really. That many of those with multiple limb disabilities report that they need support with finding a healthier lifestyle, a suitable fitness regime and understanding weight management in a way that is tailored to them. And the goal of this project is to inspire participants to a healthier lifestyle, providing the necessary knowledge and tools to achieve better health and wellbeing. And another thing they recognised was ageing with disabilities. It's important to keep a healthy lifestyle to avoid additional complications or problems. So you're talking about your diabetes, your high blood pressure, your heart problems.

The way they did it was to have a three-day long camp, three times a year and it was residential, with talks about healthy food, weight management, pain management and stress. And there were opportunities to try out fitness training such as qigong, water aerobics, Tabatha (strength training / work out / Pilates), sorry the poor interpreters are having a terrible time here, they've never heard of these words. I've described a little bit about the exercises there. But basically gentle exercises involving relaxation, stretches, keeping yourself flexible.

It started out by getting everybody to fill out a lifestyle questionnaire, which enabled individual health coaching with a professional coach. And each of the participants set themselves personal goals. So, for example, it might be to stop smoking or to lose weight and they were each provided with a personally tailored training plan and they had the opportunity to join in group discussions about pain, weight, stress, etc. Personal goal setting and then evaluation and follow up.

So participants found a form of exercise and a location that suited them. They exercised and worked on their personal goals in between attending the three step lifestyle course. They supported each other and although inspiration and knowledge are provided, the really hard work has to be done by the participants themselves.

So the result was that a local exercise group, a Pilates group, was set up in Stockholm. Health promotion has been implemented as part of the Ex-Center Rehabilitation Plan and the work of FfdN, which is the equivalent of our Thalidomide Trust, becomes more health centred in approach.

Participants reported that there was a change in the way they thought about food, the way they dealt with stress, the way they did exercise and the way they dealt with pain. They changed their diets and they used mindfulness as part of this process. They lost weight, started a daily fitness routine and they experienced less pain.

So here are just some of the results. One participant lost about one and a half stone which is nine kilograms, and experiences less pain in their back and neck and has realised that a big part of their pain was caused by the extra weight they were carrying.

Another participant lost two stone, five pounds, fifteen kilograms, after the project leader, Hanna Isaksson, arranged an education day for this person's personal assistants about exercise and healthy diet. And participants learned how to exercise without worsening their pain and it made a huge difference to participants' lifestyle; reducing stress and reducing pain.

Right, okay. I don't want to play that just yet. I hope it doesn't start up, it's going to be a video. So ... I'll just check how I'm doing for time. I'm all right for a little bit.

So Fit for the Future will be an exciting and informative Beneficiary-led weekend which will be held over the weekend 15-17 April 2016 at Burleigh Court Hotel and Conference Centre in Loughborough. You don't need to make notes, I've got some fliers which I can hand out later which will tell you all of this. The objective of the weekend is to empower thalidomiders with knowledge and tools to enable them to make informed choices in order to maintain or increase levels of independence and promote pain reduction.

So as you've heard, several times today, as we're ageing, many of us start to experience increased levels of pain, loss of flexibility, loss of function and weight gain. And whilst this might be a common complaint for many people who reach middle age, for thalidomiders these issues might cause further difficulties, in reducing their mobility, the ability for them to self-care and our ability to remain as independent as we might like to. And exercise might be difficult or even impossible and a number of us are relying on wheelchairs and support from other people around us.

The weekend will bring together experts in the field of exercise for disability nutrition and diet. And this won't just be about listening to people telling us what to do or how to change our lifestyle, it's not about a quick fix or setting unachievable goals. It's about understanding and taking the small steps in managing health and fitness in a way that fits each person's individual life and routine and can lead to long-term changes and increased health, sense of

well-being, empowerment and self-esteem. Thalidomiders will share their own experiences and stories of things they have found to help them with pain reduction, weight loss and regular exercise.

The agenda will include Anna-Carin Lagerstrom who you've heard about who basically led the project in Sweden and who has put together this wonderful book which my assistant over there is going to twirl around with... the book – where has the book gone? Sorry but, you know, I obviously didn't pay him enough money.

There's one copy of the book there that you can take a look at over the course of this weekend. It's really interesting and it's beautifully put together. She is an expert in her field. She played an integral part in the Swedish exercise project that I just described.

Some of the other speakers and experts we're hoping to have Ian Mulrooney who's a structural integrator and sports' injury therapist, Trevor and Jo Strutt, a husband and wife team who are a Pilates osteopath and Pilates instructors. Carol Atkins who's Director of the Berkshire Physiotherapy Centre, Nick Webborn who's the Sports and Exercise medicine lead at the Centre for Sport and Exercise at the University of Brighton. These are people who are already working with thalidomiders, one or more, and they've got a specialism in sports and exercise for people with disabilities.

So I think the weekend will start off by exploring what people hope to achieve over the course of the weekend. There will be a chance for everybody, as you heard in the recipe, to be shown some hydrotherapy exercises, we'll be looking at massage, learning about the benefits of Pilates and other exercise and the very important role that nutrition plays in keeping our bodies and minds healthy. We're going to have two personal trainers available who are going to talk about their role and give individuals exercises tailored to them.

And hopefully now ... I'm going to try this, I don't know if it will work. So hopefully a little video to show you the AlterG treadmill... maybe not. I don't think it's going to work. Oh, hang on, something's going on. There's no sound but this shows an above knee amputee using the treadmill for the very first time. He's never been on it before. It's quite hard to describe but the clear box you see under it is filled up with air and he's sitting on a pair of Wallace and Gromit style trousers which means it's completely airtight around his waist so he is supported by a big cushion of air. You could support 100% of your body weight, depending on how fit you are. But here he is, slowly building up to a run on the treadmill. I've had a go on this and I've used a regular treadmill and this is wonderful, you couldn't get me off of this almost. It was just a feeling of freedom and I felt I could just carry on running forever. And if you've not exercised before or if you're carrying a lot of additional weight or have a difference in your limb length, such as I have, this is just a great way to start moving. Gently at first.

We're hoping to have the AlterG treadmill there. It's a shame you can't hear the sound because this chap just basically says it's the first time he's run in nine years, since he had his amputation, and his face just says it all, He's clearly delighted I think.

We're hoping to have Beneficiaries there to share their own experiences of what works for them and I know that in the room here we've got some Beneficiaries who've found an exercise that works for them or who have lost weight by different methods but who can tell you what a massive difference that makes. And for some of you that won't make a difference, you need to do it for yourself, it doesn't matter how much people encourage you to do it. And you'll do it in your own time.

I have to say I haven't spoken ... put your hand up if you're a man in here who's lost any considerable ... because I haven't talked to any men so sorry men ... there's about four or

five women I know who have lost stones and okay ... Karl waving his microphone in the air. Sorry Karl. But you're falling behind you chaps.

We're also going to have one or two personal assistants for the duration of the event who will be there to help people because we recognise it's going to be quite physical, there will be changing in and out of swimming costumes. We want to give people the chance to have help with carrying food and opening doors and things because that will leave you more energy to participate in the activities. The weekend's designed primarily for Beneficiaries of the Trust but we recognise that some people want to bring along their own personal assistants or family members to help them and we won't discourage them for attending but there won't be a specific programme laid on for them. In fact, it would be helpful for them to be there if they're going to be part of your ongoing programme of change and encouraging you to keep it up.

There will be a charge to Beneficiaries of £200 which sounds like a lot of money but that's two nights in the hotel, the charge will be only to the Beneficiaries attending and will cover everything. The rest of the funding will come from the Departments of Health who are very supportive of what we're trying to do here, understanding that we've got the Health Grant but some people need to be encouraged to use it in a way that's going to work for them.

There's a maximum limit of 32 Beneficiaries on this weekend I'm afraid. So next weekend the Trust will send out forms for you to fill out to register your interest in this event so please do hurry up and send them back. If there is more interest than we have places then we will repeat the event. And just to remind you that I've got these little handouts here that just basically give you all the details about what we'll be doing.

So that is Fit for the Future. I've probably got a little bit of time for any questions.

Can I ask you a question – the AlterG treadmill? Where does one find out if there's one near to them because it doesn't look like the sort of kind of thing that every mainstream gym might have ...

SI: Yes. If you look on the AlterG website which is an international website, and you put in your postcode and it does tell you about any near to you. I know that the nearest to me, which is probably the nearest to you, is Chiswick or I think there's one in Aylesbury so they are quite a distance and I think they cost, I think it's something like ... don't quote me on this but something like £40,000. But I think they are starting to pop up all over the place because they're very useful for top athletes who have got injuries and need to keep on training when they're injured. Like you Karl.

Can I just chip in on that to say one of the things that we discovered is a lot of football clubs have the AlterG machines because if footballers get injured they want them to get back to full fitness without putting pressure on. And one of the things we're trying to negotiate with some football clubs is to have sessions that are going

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