

**Health & Wellbeing
Carolyn Desforges
Dr Mark Chorlton – Transcript to follow**

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00:58:16

CD: Thank you. I'm actually delivering ... sorry, my name is Carolyn Desforges. I just came onto the NAC in April. I'm just finding my feet. I'm a bit nervous about standing up here actually because I've not done it in front of everybody here before. But it is nice to be here and it's been a very interesting and enjoyable six months so far.

I'm actually presenting Dee's talk for her so I'm going to read it because she's got some very specific things she wants to say.

Knowledge is power, information is liberating. Some of you who came to NACAC in 2013 will recognise this quite from a talk from Dr Dee. This is an update on the on-going work since and will take about twenty minutes. The talk is split into two sections.

Firstly, the projects and research that have been done and are being done to develop the Trust's knowledge on health issues affecting you and then, most importantly, how the Trust uses that knowledge to help you. I'm not going to take questions and answers at the end of this because obviously it's Dee's talk but she says please do email her or give her a ring later on.

So firstly, what projects and research are being done to help our knowledge of the issues that are affecting us? You may already know of some of them already particularly if you've been to NACAC before or if you've been reading about them in the Trust and the NAC newsletters.

If I look first at projects around the world, there are two in particular that the Trust have been following. The Trust has long been aware of issues we face with trying to control weight and trying to find suitable exercises. We know weight gain is even more of an issue as we get older. We know that the more weight we carry, the more difficult it is for us to get around and this makes any existing disability from thalidomide even worse. We know ... also know that some of us don't know how to exercise safely.

Two years ago the Trust became aware of a project in Sweden of managing lifestyle by exercise and diet. After looking at the project, the Trust decided it was a very worthwhile project and that it would follow the project together ... and that it would follow the project, together with the NAC, rather than do any of its own in-house research on these issues. The Swedish team came over in April and presented their findings to the Trust Health and Wellbeing meeting. More of this later.

The second most important recent project has taken place in Germany. Again, you may well have heard it. It's known as the Cologne report or, more accurately, the North-Rhine Westphalia Study. The study's purpose was to see how best the German's health insurance system and care system could provide for those affected by thalidomide in the future. This was a very large project involving 200 people affected by thalidomide who filled in questionnaires, were examined and had scans

or x-rays. It looked at the damage the individuals were born with but also any secondary damage that had occurred with age.

Very briefly the results were: they felt the doctors and carers were not properly informed about thalidomide and its effects. In particular, they felt the doctors were not respecting the fact that many affected by thalidomide do not like taking tablets and therefore they don't like taking painkillers because of the thalidomide and what it had done to them and people needed more reassurance to take tablets. They felt the doctors weren't prescribing enough physiotherapy, massage therapy or pain relief. They felt these therapies should be available during a stay in hospital, to help rehabilitate them. They felt their care system was not prepared for them as they grow older and have increasing needs. Interestingly, a large proportion, 80% of the group, were actually working but only 50% had adaptations in place. They felt that not enough was being done to help them with work. They felt they needed to identify the people who are more vulnerable, encourage lifestyle alterations to prevent further damage, train doctors to help individuals understand the need to take tablets, particularly painkillers. They also felt doctors should be able to refer individuals more easily for gadgets and gizmos, that individuals should find it easier to get financial help with health costs and have a better awareness of mental health issues.

So what did the Germans decide to do about it? Well, the project resulted in a fund being set aside to which individuals could apply with attached criteria. For example, identified therapies, massage, physiotherapy, also aids and adaptations for gadgets and gizmos as HealthLink calls them. It resulted in the setting up of more specialised centres where doctors could receive specialist training in helping with pain, together with the facility for a stay in hospital for physiotherapy, massage and acupuncture.

So if I turn back now to the Trust and the projects in the UK. Firstly, the Nerve Study, you should all be aware of the Nerve Study with Charing Cross. We were sent a letter about it with the results of the study. Since that time, Charing Cross has been trying to get the paper published. It was suggested they did some more work on it to make it more robust. The Trust had questions about their work and, until the paper is published, the Trust cannot openly discuss the work with other people. So the Trust requested their own independent review from a very knowledgeable doctor at Oxford University. Importantly, the review agreed with the study that if you have pain, pins and needles, numbness then it is important you go to your GP and be referred to find the cause. This is because it's very likely the cause may be a trapped nerve that could be freed. For example, carpal tunnel, where the nerve is trapped in the wrist. However, two individuals have had trapped nerves in the neck and needed an urgent opinion to prevent serious long-term damage. Australasia has since published a paper saying exactly the same things.

The review from Oxford on the Charing Cross study did differ to some extent. It differed with respect to the fact that the Trust had wondered if we might have a condition similar to what happens to individuals who contract polio. Polio causes paralysis where the motor nerves are affected and the muscles don't work. So initially, an individual may not be able to move their leg. The individual then recovers, to some extent, for example, they could move the leg but the muscles are weaker and they might have a limp. However, as the individual ages, the body cannot maintain that recovery and the nerves get worse. Again, this condition is called Post-Polio Syndrome. However, the review did assure the Trust that this condition is not happening in ourselves. The nerves controlling movement are not affected, so that's very good news.

If you remember, our letter said that there was some possibility of an underlying nerve problem as we aged. This is because the study looked at individuals with damaged arms but relatively normal legs. Some of the nerve tests on the legs had come back abnormal. The review did find some evidence that nerves the tested in undamaged legs were affected. However, the review felt it was not possible to know whether the individual had been born like this, which could be the most likely explanation or if, in fact, the nerves had changed with age which the study had focused more on. Hence, the review suggested the conclusion was changed, suggesting there was only some evidence of a problem with nerves as we get older. Dee says this may be hard for us to understand but later in the talk ... explains what the Trust are doing about it.

Another project is blood pressure recall. The Trust's Blood Pressure Project with Professor Williams and his team at University College London ... I'm going to call it UCL from now on. If you remember this is to help those who cannot have blood pressure taken in the normal way, with a cuff on the upper arm. It is also for those who may need more reassurance as the need to take tablets for life to help blood pressure and prevent a heart attack or stroke.

Where are we now? This study has ethics approval and this makes it safe and fair to ourselves. The study has also received a national stamp of approval and has been included in a national set of studies, thought to be very important in helping care for the general population of patients. We have agreement from the Health Departments of England, Scotland, Wales and Ireland that your GP can refer us, on the NHS, to the clinic in London if we meet the criteria for this study. Some individuals have been referred by their GPs, with the help of the Trust, to be the first ones through the clinical study. They will help us make sure everything runs smoothly, that the accommodation is okay, and that all the tests can happen in one day. So they're like the guinea pigs.

The start of the study has been very delayed. UCL told the Trust it was because they were moving the clinic and this would make it much better. And they also had to coordinate our research with other studies they were also doing. Once UCL have seen these individuals and they know it's working well, we will openly write to you all and invite you to take part and explain how to do so. This is if we meet the criteria and live in the UK.

I just wanted to remind you of the importance of the study, the stamp of approval it has and that other countries are awaiting the results to see how they can help their own individuals. Please remember this when you receive the invite and are considering whether or not to go.

Another project: the Upper Limb Project. Again, we may have heard of this project before. The project was to help individuals who had a difficulty of diagnosis on their arm pain. Either because the GP would not refer them or the GP didn't know who to refer them to or they felt they had an opinion and needed more reassurance as to whether or not to trust it and take it further. Hence the Trust funded a private opinion and tests with Professor Trail at Wrightington Hospital so that a diagnosis could be reached and options for treatment could be discussed. All those who fed back said it had been very worthwhile and wanted this to be available to other Beneficiaries in similar circumstances. The Trust has continued this project on looking at all thalidomide damage and where best individuals can get to help.

Another project: Dr Cowan. Last year, Dr Cowan from the Royal National Orthopaedic Hospital, just North of London, gave a talk at NACAC here. Dr Cowan is

a very eminent bone and nerve doctor specialising in helping those with difficult problems. The Trust involved Dr Cowan because individuals were telling us they were concerned they had underlying issues they felt might be due to thalidomide and because other countries were looking at specialised centres and we wondered if we needed one. Dr Cowan has been seeing anyone who wishes to go and see him, with help from HealthLink.

So how can he help? He has helped individuals sort out their own issues. To talk them through and if needed advise their GP what tests to do and for the individual to have them done near to where they live. He has also suggested treatments to help, lifestyle advice such as found in the Swedish study with exercise but also physiotherapy and rehab programmes. Again, to be provided locally to where people live. He is able to provide a stay in hospital for physiotherapy etc. similar to what Germany is setting up. However, he has not felt the need to suggest this and, if he has, the individual has not wanted to access it. He has specifically helped the more severely affected in the group with more complex conditions that the Trust and GP had been very concerned about. Not necessarily with limb issue problems. He has sometimes requested the GP refer the individual onto other specialists familiar with thalidomide limb damage with the help of the Trust, such as shoulder specialists, wrist specialists, often within the RNOH, his own hospital. He cannot find any underlying common issues amongst us all that require a specific specialist centre outside the ones that have already been identified.

If you remember, I mentioned before the nerve study, that they'd worried if there was an underlying problem with nerves. To remind you, this is because some of the nerves of the undamaged legs were abnormal with special testing. Doctor Cowan has not done tests but he has looked to see if the nerves are causing any problem. This means he has asked specific questions to see if the individual has any symptoms and check to see if the nerves are working properly on examination. So far, these ... both these areas, the nerves are working fine. This is very good news and supports the Nerve Study Review findings that it is more likely that the specified testing of the nerves in the legs show problems that have actually been there since birth rather than the Nerve Study findings where the nerves are getting worse with age. Sorry, that was a bit complicated. So basically any problems with the nerves are there from birth, they're not being acquired as we get older, which again is good news.

Right, I've gone through how we develop our knowledge of the issues that affect us all. Now, I'm going to explain how the knowledge that has been acquired through this research is being used to help us. And, as said, this is the most important area.

I've explained how weight and exercise have long been issues known to the Trust. So how does the project of the Swedish lifestyle, and its effect on pain, help you? Well the work has been used to underpin the Fit for the Future event that is being held by the NAC in April next year and Simone's going to fill us in about that later on. There's a lot of hard work been done on that.

The book they used is available free of charge by the internet and, do you know, I'm really annoyed because I've got a copy at home and I meant to pick it up and wave it at you. But it is very good so it would be worth looking it up on the internet, I found it really interesting and, if you wish a link to this, please email the Trust. It is a very good read; it's very clear and easy to follow.

M1: Sorry, what was the name of the book?

CD: do you know what? I can't remember what it's called. Simone ...

SI: I've got a copy ...

CD: You've got a copy ...

SI: ... with me. If anybody wants to look. And the recent NAC newsletter also has a link to ... where you can view it ...

CD: Fantastic. Maybe Simone after lunch ... do you think you could get it at lunchtime and we'll sort of wave it around for people to look at?

SI: I brought it to wave around in my speech.

CD: Oh, okay. We'll wait for Simone to wave it around then. Okay.

How are we using the Cologne Report information? The Trust has liaised with the authors of the report and paid for an English translation. This has been agreed with Germany. As soon as the report is openly published in Germany, the Trust will put it on the website so any of us or any English speaking healthcare professional abroad, who wishes to read it, can do so.

So I've given you already a summary of the main findings of the report. They said specialised centres, a fund for physiotherapy and gadgets and gizmos, having more informed doctors better able to help with pain.

So how does this knowledge fit with what we're doing here? From our questionnaires and Dr Cowan's work, individuals in the UK prefer physiotherapy, massage and rehab programmes near to where we live and not in a specialist centre. We don't want to travel miles for it. Doctor Cowan does not see a need for such therapies to be in a centre but his own hospital already can provide for this and other conditions if a particular individual needs to access this.

We are lucky enough to have the Health Grant which, as mentioned ... oh, I think it was in the finance one, can be used for private physio and massage on top of what the NHS can provide and gives us a much wider choice of what it can be used for other than the specific fund that they are recommending in Germany. Nearly at the end. It will advise you whether or not we need to take ... have I gone to the right page here? Sorry ... sorry, I forgot to turn over. We have much knowledge in the Trust of thalidomide and its damage. And we have experienced specialists in certain hospitals we work with who are already familiar with thalidomide and how to help.

For joint and spine issues in particular we work with two hospitals, if individuals are prepared to travel. And these are the RNOH, already mentioned, and the Wrightington where the Upper Limb Project took place. Where we suggest for other thalidomide damage varies as to where the best experts are. Hence, we feel, the areas raised in the report have already been looked at in the Trust and will continue

to be. For example, there's always ongoing work around pain and how to help it. We also await the Firefly report from the questionnaire that over 75% of us have recently filled in and we will revisit the above areas if necessary.

How do the results of the nerve study help us? We've sent everybody a letter to give to our GPs in case we need a referral for pain, pins and needles and numbness. HealthLink continues to support anybody having difficulty obtaining this. With regard to any underlying nerve problem, as I have explained, Dr Cowan is continuing to see anybody he sees for this. In addition, the Trust has asked UCL to include a test of the nerves and the blood pressure study, another reason why it is important for you to go to the study if you meet the criteria for the blood pressure. Hence, again, currently we feel we are doing as much as we can to take this forward and be certain there's no new damage on the nerves with age.

So, finally, the work on blood pressure, how does this help us? If we have difficulty having a blood pressure taken in the upper arm, the Trust has already written leaflets to say the best way that this can be done. These are available via HealthLink but are also available on the website and I have taken mine to my GP already. These leaflets have been shared across the world: for example, to Canada, Australia and EDRIC. The Blood Pressure Study will, as I've explained, help us, as individuals, know about our risk of heart attack or stroke and how this is best measured in the future. It will advise us whether or not we need to take tablets to reduce this risk and, if so, which ones are best for us to avoid the need to have blood tests to monitor them in the future. This advice has come from the best experts in blood pressure in the UK. The study will allow UCL to act as a specialist centre, not only for the UK and not only for limb damage caused from thalidomide. This means it will help other groups, such as those with TAR Syndrome, etc. and it will develop an international reputation, advising doctors abroad of different ways of taking blood pressure.

The Upper Limb Project with Professor Trail helps HealthLink know how best to help us as individuals with thalidomide damage. How to help our GPs and how we can get the best help from experts familiar with thalidomide damage, depending on how far we are prepared to travel.

So I have gone through what has been done and what is being done by the Trust and others to try to develop our knowledge of the health issues affecting us and how this knowledge is used to help us.

Knowledge is power, information is liberating. If you have any questions, please email Dr. Dee.

So, following that, thank you trusted assistant. As I say, I'm not going to take questions now. I think Carl was very good at keeping up with me there. But also, I think, linking on with this, I'm going to move and pass onto Dr Mark Chorlton who's come all the way from Australia, New South Wales. He's going to introduce himself but I think managing pain is a big issue for many of us and I've already had a preview of what he's going to say and it's really interesting so I'm going to pass over to Mark.

MC

M2: [Unclear 37:02]

MC:

M2: Or will it get worse?

MC:

F1: 18 something ... ?

F2: [Unclear 53:09].

MC

F2: [Unclear 53:15].

F3: Hazel can you wait for the microphone?

F2: What?

F3: Can you wait for the microphone rather than engaging in another conversation.

F2: [Unclear 53:23].

MC

F4: I was just wondering what your opinion was and I'm just solely speaking from my personal experience of distraction techniques like comedy, music. I found, at times where I was in a situation where medically there was nothing that was going to take the pain away, that it was something I needed to go through, the therapy I was having. And I think that it was those sort of distraction techniques when I said, "Right, I've had enough. Get me my music. Give me my space and I'm going into a different zone."

MC:

F5: Okay. Maybe one more question.

F2: This isn't actually a question, it's just to clarify what I was saying to Mark earlier when he said about the TENS machine for me personally my experience with the TENS machine, even on the lowest setting, it actually made my pain worse so it doesn't work for everyone.

MC:

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