

**HealthLink**

**24/10/2015 NACAC**

**00:17:03**

**AH:** Anne Horton

**MR:** Michelle-Jane Robinson

**EB:** Emily Bates

**AH:** Okay, hello folks, the NAC have asked me to talk to you about HealthLink. Carolyn said she was reading Dee's talk because she wasn't Dee, meanwhile, I'm reading mine because I'm me. So ...

HealthLink has been running for 8 years now and I'm sure a number of you have heard me talk about it before. So I'm going to try and focus on what's new, what's next and also on some of the common myths and misconceptions about HealthLink.

I want to start off with the exciting news that the HealthLink team has changed since I last spoke with you. We have two new staff with us now. First, there's Michelle Jane who's a great support to the whole team, she's been with us for a while. Some of you have spoken with her already as she is usually the first person you speak to when you call HealthLink now. Michelle Jane knows the HealthLink team and who can best support you with your enquiry. Michelle can ask one of the team to call you back and, this way, the phone bill sits with the Thalidomide Trust and your call will be dealt with as quickly as possible.

Secondly, we have Emily, our new HealthLink coordinator, who has literally just started with us two days ago. We're literally throwing her in at the deep end here today but she's keen to get to know you and I'm keen to share my work hours with her. I'm going to ask both Michelle Jane and Emily to introduce themselves as I know how important it is to put a face to a name and then they can tell you a bit about their background and how best they can help you.

But first I just want to mention how sorry Dee is that she couldn't be here this year. I think it's been mentioned before that she's away because of half term.

So can we just hear from Michelle Jane and Emily please?

**MR:** Can you hear me now?

**All:** Yes!

**MR:** Is it too loud?

**All:** No!

**MR:** I'm normally told I can be heard in Newcastle. I'm Michelle Jane, I'm usually the first point of contact you hear when you ring up the HealthLink number. I've spoken to a few of you here today and it's so great to finally put a face to a name, to be honest with you, it's lovely. As Anne says, I am the first point of contact. Normally I can't always answer the queries you have but I know which person to actually refer them on to. To Anne, to Dee or, now, to Emily. So if you've got any queries or concerns at any time, please do give us a call because we're there to help and support you. Okay?

**AH:** Emily.

**EB:** Hello. So I'm Emily and I'm a qualified social worker. Yes ... I knew it would come. But believe it or not I am here to fight your corner. So my background is in social work and I have spent nine years working in the voluntary sector working for Parkinson's UK. And my role with the Thalidomide Trust is mainly to help you around social care issues and any other concerns that you might have as well. But I have some knowledge on benefits in general so if there's ... I can help you if you've got any concerns or queries. So with the move from Disability Allowance to PIP and some people will be having their reassessments soon so if you've got any questions or queries, do come through Michelle. Also if people are having any social care at the moment or thinking about social care, direct payments, I can help you there also and advise you around that. And I always say to people if you've got any concerns, any queries, please come to us, as the HealthLink team in general and if we don't know the answers, we try to find somebody who does. So that's it. Okay.

And I'm really fortunate ... I feel fortunate to be here today because I only started on Wednesday so I've got the opportunity to actually meet a lot of you. So thanks. Bye.

**AH:** Thanks Michelle and Emily. Right. So as you can see, our skill base has grown with the changing of the team. You still have Dee Morrison to talk with regards any medical issues and that's a wide remit she covers. And then there's me, with my occupational therapy knowledge, to deal with issues around independence, mobility and day to day living. But now we have increased expertise and capacity in terms of both social care, how health and social care fit together and benefits. Definitely phone Emily if you want to talk about benefits. Not me.

Right and please don't forget the HealthLink team is able to draw on knowledge and expertise from outside the team whether that's from one of our Volunteer Visitors or VTag team, members of the NAC, outside experts or even other Beneficiaries who are willing to share their experience and knowledge of particular issues.

I mentioned that I was going talk about the key misconceptions about HealthLink. So what are they? It seems, rumour has it, that HealthLink is merely a telephone advice line. You have to be really struggling before you get in touch with HealthLink, it's only for really serious problems. You can only contact HealthLink about medical issues. So picking up on these points, for the majority of Beneficiaries who do choose to call us, the new team number is 01480 226 769. But we know that people like to communicate with us in different ways. So you can also email us on a team email: [healthlink@thalidomidetrust.org](mailto:healthlink@thalidomidetrust.org). Or even write to us if it's easier to write things down in a letter. Please address the envelope to HealthLink at the usual Thalidomide Trust address.

Not only has the ways that Beneficiaries contact us changed but the number of you getting in touch has increased too. Over the last six months 169 Beneficiaries have been in contact with HealthLink, that's more than one in three of you. And it's not all about people struggling, some of you just had a quick question for us or wanted to talk something through that your doctor mentioned. We are used to dealing with people in crisis and we can do this but we do prefer if you phone before the issue becomes a crisis as it's easier really for you if you allow yourself some time to try a few things out.

In terms of the things that you can contact us about, well there are no rules about this. Obviously you can get in touch with us about every day and medical problems, and, as you get older, we have noted that some of you are dealing with quite complex medical issues. You can also get in touch with us about anything that affects your health and wellbeing. Think about your health; how it's impacting on your everyday living, driving, socialising, getting away on holiday, how you're coping 24/7. Stop and ask yourself: do you feel something needs to change really because small planned changes can make very big differences.

If there's something bothering you or something you need further information about, and you're not sure if it's appropriate to raise it with HealthLink, please just call anyway and drop us an email. If we can help, we will, and if we can't we hopefully will know who to signpost you to.

Perhaps the easiest way to give you a flavour of the issues the team can help you with is to give you some examples of the ways we've been able to help Beneficiaries over the last year.

Dee has often spoken with GPs and sent letters to explain the knock on effect thalidomide damage has on other health issues. An example of this is where someone with reduced length arms with a new knee problem was really struggling and the GP simply wasn't referring them on to a consultant. HealthLink wrote to the GP advising how it wasn't safe for him to come downstairs; his leg was giving way and he couldn't support himself on the handrail. This type of intervention helped push the GP into referring sooner than he otherwise would have done.

Sometimes Dee advises the GP about specialists who have a good knowledge of thalidomide and have seen other Beneficiaries. We have well used lists of consultants who for example, know all about backs, shoulders and hips. HealthLink can't make the decision for you on who you see, that really is up to you and your GP but the information and knowledge that Dee has can help your GP make an out of areas referral for you.

More recently, Dee has researched and found a consultant who has reconstructed an ear from cartilage, using the latest techniques and another who has offered facial reanimation to even up the facial appearance. And she's also found a specialist to undertake epidural in the neck at the local pain clinic said it was too difficult.

Dee has supported a Beneficiary who had concerns about having a general anaesthetic by discussing this fact with the surgeon. Dee has also written a letter to a housing department to explain why a Beneficiary has specific needs in terms of the type of accommodation

and she can help support you if you're having problems at work, by writing a letter of support to your occupational health department, outlining how your current thalidomide-related health issues are impacting on your role at work.

We have Factsheets about how best to take blood samples and can lend an expensive gadget called a vein viewer to your GP practice for anyone struggling to give blood samples.

We're currently helping someone who is about to lose his Motability car as a re-decision led to him losing his higher rate mobility, now top level PIP which is a qualifier for the mobility scheme. We have Factsheets on this if anyone's interested. Please do let me know and we'll send one out to you. The topic of Motability and PIP is where knowing the facts ahead of time helps, but you really don't need to do anything until the DWP contacts you about the PIP assessment really. I now have a very helpful contact at Motability and she has helped signpost a few people for more support within the Motability scheme and she's helped one person who had problems extending the lease on the car and also somebody who had problems putting their carer on the insurance because they lived more than five miles away. I have actually found Motability very, very helpful these last few years, these days they seem to be able to now make exceptions to their rules and you can actually lease your car for up to ten years if you've got very expensive gadgets on it.

Another thing that I've been involved with this year in particular is helping people renew their Blue Badge and now I have a factsheet on it and also a letter that will help support you.

I've provided information about car adaptations and garages that are helpful and driving assessment centres and with help from some of you, I have begun visiting some of these centres and garages to build useful links and to start a knowledge base about them.

This year seems to have been the year to focus on foot steering and I know a lot more on the topic because of this. Liz Buckle kindly sussed out three of the garages and an assessment centre on the topic and I will add her insights to the factsheet that I'm about to write. Liz will shortly be setting up a Facebook group for any foot steerers to join.

The list of examples could be much longer but there isn't much time to cover it today so all I'd like to do is reiterate the message that if you have a query, please don't hesitate to give us a try.

If you contact the HealthLink team we will always listen and try to understand, give you space, we recognise you might find it hard to talk about some stuff and we'll go at your pace. We'll help you understand your health issues and to understand the support solutions that might be available. But it's not a one way process, if you get in touch with HealthLink, we can hopefully provide you with the information, advice and support you need to help with the challenge you are facing, but we also learn from you. By understanding more about your health issues and the challenges you are facing, it enables the Trust to increase our understanding of Beneficiaries needs generally and if we undertake research to find a solution to a problem that you're grappling with, the chances are that there would be other Beneficiaries who would benefit from that information too. So one of the most recent changes we have made to HealthLink is to turn that information, we have pulled together into factsheets and we're going to be putting that up as web copy soon.

When we set up HealthLink it was very much in response to hearing Beneficiaries say that their GPs had told them that all their problems were all to do with thalidomide and could only get worse and if you or your GP still think along those

lines, please contact us, read the information we have, talk to others in the group because that just isn't the case.

HealthLink is now in a position to support you to move forwards and be heard. We have listened and learned and responded to the needs we have heard about. We have built connections with experts in all sorts of areas and that means when a new enquiry-comes in we have the staff ready in place for an answer. We might need to do some more research, we might need to join up some more of the jigsaw but we're on one of the rungs of the ladder instead of at the starting point.

Hopefully the presentation today shows there are answers and solutions and we have the potential to help any one of you who calls.

So where do we go next? We want to continue to improve HealthLink, to increase our knowledge and expertise in new areas that are important to you, to collate more fact sheets, share more information, add to our list of consultants and experts in various topics and improve our communication. On a personal level, over the next twelve months, I plan to focus on increasing my knowledge of wheelchairs and house adaptations and I hope that you'll help me with this and, in return, help other Beneficiaries. You are the experts and I would really like it if you would send in pictures of what you've found works for you. Just please tell me about it. What wheelchair works well indoors, what ones work well outdoors, what's the improvement that you made in the kitchen that's made the biggest difference, are there any particular kitchen designers or installation companies that you would recommend to others? If we create a fact sheet on those topics, it will help those of you who are newly seeking the right wheelchair or the right adaptation for your home. It creates a shortlist of models of wheelchair to trial or kitchens to research.

Finally, I'd like to thank the VTag group for their help resourcing and providing gadgets to purchase for the gadget stand outside. Thank you for listening.

## **END OF RECORDING**