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WHAT ABOUT THE CARER?

Interview with Therese and Stephen

Stephen: It feels like there's a truck parked on my leg and it's just been crushed. I can try and mask it with medication, try and ignore it, but it's always there.

Therese: His whole personality has changed, the medication affects his thought processes, emotionally he's quite fragile at times, so really you know from the man that I married he's extremely different.

Richard: I'm Richard Fox and this is Messages of Hope. One in Five Australians suffer chronic pain. It can be a debilitating condition, leading to personality changes and a heavy strain on relationships. First thoughts often go to the person suffering the condition but what about the carers? Today's guests are Stephen and Therese. 14 years ago Therese went from being a wife, mum and teacher to also being a carer of her husband Stephen. He's been suffering from chronic pain since 2003 with no hope of a cure. Therese, how has life changed for you since Stephen was diagnosed with Chronic Pain?

Therese: I've become his carer and his protector. That role of changing from being a wife to that element of carer, that's massive and very draining at times. His whole personality has changed, the medication affects his thought processes, emotionally he's quite fragile at times, so really you know from the man that I married he's extremely different. And then too, trying to compensate as a parent for Joash, sometimes I feel like I have to be both mum and dad because Stephen can't do the dad things that a dad would normally do with their son.

Richard: And how have you felt about those changes?

Therese: I went through a time of a lot of anger, a lot of anger at God for why did this have to happen to us? We had the world at our feet but I think I learned that just continually asking that is just wasting time and you just keep living in this anger and this frustration that is not quality life.

Therese: at some point it just has to be acceptance, otherwise life just passes by and you're always looking for that solution whereas I think that for us until we accepted it, we couldn't actually move forward.

But it took a while, took quite a while to come to terms with and just let go of that anger.

Richard: Stephen, What ongoing challenges do you face as a family?

Stephen: The big challenge is when it's school holidays and Therese is at home and our son is at home and they want to do things and come up with things spontaneously. I have to divorce myself from this and just say "I can't do this", my condition won't let me do this and then the realisation hits as to how bad this actually is. It's then, when I can't do those normal things, that it becomes emotionally difficult. And you know every school holidays I think each of us in the family faces that and each of us either cries or gets angry.

Therese: Everybody has their day.

Stephen: Everyone has a breakdown at some point.

Therese: We don't all have them at the same time which is good.

Stephen: So you look after that person while they're breaking down and then later on you break down.

Therese: You know I don't think emotionally Stephen's always aware of how it's taking a toll and therefore the way he speaks to me or to Joash, you know... you always take out things on your loved ones. Joash and I just always say it's the pain talking, it's not dad talking.

Stephen: The more I've talked with others beset by medical limitations or illness or disease or disablement, often it's the partner, the wife, who has the bigger challenge when they see their loved one disabled or crippled or hurt, daily. I actually think it's them that have the harder time and often that gets forgotten. You know people come up and will ask Therese about me and I'm ok. God's looked after me - with her. But what about her - you know, what about the carer and that role?

Richard: What do you feel about that Therese?

Therese: It drives me nuts, particularly if it's people that I haven't seen for a long time and the first thing they say to me is 'How is Stephen?' I kind of feel like I'm a person too and it makes me feel like I'm a bit insignificant. I know people don't intend to make me feel like that, it's just the care and the concern they have for Stephen, but sometimes it just comes out wrong.

Richard: So how do you face up to each day as it comes along?

Therese: How do I look at each day as it comes? Sometimes I'm just terrified. Work has been my rest sometimes, my escape and I think that's what's challenging about holidays. It's really difficult to see your partner in constant pain twenty four hours a day, seven days a week. At least I get a break from it, like it's always in the back of my head but it's not just full on in your face. So work is an escape for me but it's also then a fairly big stress. I've got a family to run, I've got a job to go to, I'm the bread winner and I want to be a role model to Joash that despite what life throws at you, you still keep moving on.

Richard: The carer of someone with a long term illness is often forgotten. They also need support, to cope with the emotional and physical demands. Therese what's helped you to keep going over the last 14 years, since your husband Stephen was diagnosed with Chronic Pain?

Therese: It's probably only four or five years into this injury that I realised I need to have a break and it's not selfish of me to say "Look, I need to go away, I need to have just a couple of days to myself". I now do that every six months.

Stephen: Carers leave.

Therese: Yep and I need to not feel guilty about that.

Stephen: I think being given permission by our psychologist is really important just to say you need this.

Therese: And I think too that Stephen gives me permission and Joash quite enjoys it when mum goes away (laughter), he's always happy when his mum goes away.

Stephen: Apart from the few hours of cleaning the house before mum gets back!

Therese: (laughter) But I can only do that with the blessing of my family and I get that wholeheartedly

Richard: I know some people try and avoid seeing psychologists or doctors because they feel it makes them appear weak and can't handle life. What do you say to that?

Therese: I was one of them!

Stephen: I had to drag Therese kicking and screaming

Therese: and even still sometimes. It's like, "Oh do we have to go to the psychologist? I've just worked all day and I don't feel like it." I thought it was ...I don't need that. I can cope with this all. but then it was just that other opinion and that other input, that other view that was just really helpful!

Stephen: and I just view it like if you don't get your car serviced it will not work and then you'll be going why isn't my car working? Well because you haven't taken it to a specialist who knows how cars work!... So it's the same with your head

Therese: and your relationships

Richard: What advice would you give to other people who want to support you in some way?

Therese: I think be specific. Be specific in I'm going to come and I'd like to pick up your ironing for you and do it or I'm going to come and mow the lawn or I've got an hour this Saturday afternoon let me come and do some gardening. I still find it hard to, if someone says oh let me know if we can help, I often still don't take them up on it but if it's something specific it's much easier to then say yes and then accept it.

Stephen: Yeah and then it gives you the freedom to say "Well look actually if you're gonna come can you actually do this?" There's actually then this freedom too then, for the receiver to be a bit more directional for where they actually need help. Yeah, that's a really big thing!

Therese: I think too for us, what's been really helpful, are those friends that are just completely understanding. A few weeks ago we were supposed to be going to friends and Stephen just couldn't leave the house and they were just so understanding and just packed up everything, brought it all over here, cooked dinner for us and so we still have that social time but Stephen didn't have to go out and they were just so flexible in that. I think that comes with having a deeper relationship with friends that take the time to find out exactly what works for us. So yeah, that's helpful.

Richard: Therese, at the beginning of today's program you said that Stephen is very different to the man you married. How have you come to terms with that?

Therese: I married Stephen for better for worse, in sickness and in health and so aside from standing by those vows he is still my soul mate, he is still the person I know I'm meant to spend the rest of my life with. No matter what gets thrown at us. When one of us is down the other is usually the strong one and we just pick each other up and are just committed to y'know seeing it through and holding our family together and showing Joash that despite struggles in life that yeah God will get you through it.

Richard: Have you become a carer for someone love? The extra demands can be exhausting and even if you don't believe in God you can find yourself crying out to him for help. If you're struggling as a carer contact us for the free booklet CHRONIC. It's written by our guests today, Stephen and Therese. They share their journey of managing chronic pain, both physically, and spiritually and where they've found the support to keep them going. For your free copy of CHRONIC, phone Freecall 1800 353 350, or request the booklet online at messagesofhope.org.au.

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