

A photograph of a man and a woman walking on a green lawn in front of a brick house. The man, on the left, has white hair and is wearing a grey t-shirt with a graphic, dark blue jeans, and white sneakers. He is using a black cane and has a serious expression. The woman, on the right, has short brown hair and is wearing a black top, dark blue jeans, and a purple sash. She is smiling and has her arm around the man's waist. In the background, there is a brick house with a patio area featuring a table and chairs under a blue umbrella. The sky is overcast.

by Paul Freedman

BRAIN-DRAIN!

struck down by a stroke

A CONVERSATION WITH MAX & LYNDA POLLARD

Of all the ills that can mess-up our lives, few are as well-named as the deadly 'STROKE' – known in medical circles as a 'cerebrovascular accident' (CVA). Stroke is the third largest killer today, and currently more than 45,000 Kiwi stroke 'survivors' (to say nothing of their families and care-givers) are having to cope with lives changed beyond recognition.

Strokes happen when brain cells suddenly die. Sometimes a blood-clot blocks a brain artery, starving the downstream brain cells of life-giving oxygen. Other times, a weakened artery swells up and bursts *inside* the brain (this is called an aneurysm), drowning those same brain cells in a blood-flood.

Every brain is different. We've each been actively building and adapting our brains all through our lives, hooking up billions of little switches (neurons) in fantastically complex patterns that govern our ability to think, feel, calculate, talk, tap our toes to a catchy tune, and so on. In fact, these little guys truly make us 'US' ... and when they die, our personality falls apart. The more severe the stroke, the more brain cells are affected, and the more we're impaired.

Grapevine recently spent an afternoon with Max and Lynda Pollard. Max is 63. Prior to his stroke, four years ago, he was the busy pastor of a flourishing church near Hamilton. His wife, Lynda, was also deeply involved in church-life and in the community.

But, suddenly and without warning, the stroke swept away their lifestyle in a one brief, tragic moment.

Max walks unsteadily now, with a stick, and tires quickly. He speaks slowly, at times with a trace of slurring – and he thinks carefully before each answer, fishing with effort in his damaged memory for the words and recollections he seeks. Lynda is supportive and dedicated – but the strain of four years as helper, interpreter and chief care-giver clearly shows. Both have been plunged into a chaotic private world. Many familiar routines have been destroyed and their lives have been altered in ways that can be agonizing.

So, what's it like living in the aftermath of stroke?

MAX: It's like ... being in a tsunami. I've never actually *been* in one but I can imagine what it must be like. And that's how I felt. It hit me like a tidal wave and washed everything away ...overwhelmed me ... in every way.

GRAPEVINE: Did you have any idea what was going on?

MAX: No. It happened one night in bed. When I got up next morning I found I couldn't get dressed. We realised something ... awful had happened.

Lynda said, "Well, you'd better go to Accident and Emergency." So we went. And it was while we were there, the next day, that I had another stroke ... and that really finished things off for me.

LYNDA: The first one happened on a Sunday morning. He was getting ready for church, and I was in the kitchen preparing lunch. I thought, "He's taking a long time. I'd better check he hasn't gone back to sleep." So I popped into the bedroom and I'll never

forget the sight. Max was just stooped there. One side of his face had dropped, and he was drooling. He had tried to put on a green singlet and it was all wrong.

I knew straight away something serious was happening. I asked him, "Are you feeling a bit funny?" "No, no," he said. "I just can't put my singlet on. Just need a bit of help!"

So I asked, "Are you feeling unwell?" And no, he insisted that he just couldn't get his singlet on. I said, "I think we need to go to the hospital." "No, no, no. I've got to take the service!"

Well, anyway, we *did* finally go to the hospital ...

GRAPEVINE: Did the doctor give you any idea how severe Max's stroke was?

LYNDA: Max had *two* strokes. The first was caused by a little clot at the base of his head. That was on the Sunday morning.

After doing tests, the doctor at A&E told us there was this powerful drug



to break up the clot ... but it had to be administered *within three hours* of the stroke: "So what time did he have the stroke?" I said I didn't know. "Well, when did you discover him?" I said I thought about 7:30am ... but I really wasn't sure. By now it was after 10:00am, so time was tight.

The doctor told us the drug could "reduce the bad effects of the stroke." At this stage, Max could still walk and use his arm – although it had little feeling. But the doctor warned us, "It could also be catastrophic. Maybe even kill him!"

Max had been given a scan, and we were wheeling through endless corridors with the doctor talking, talking, talking ... stuff about benefits, dangers, side-effects. I could hardly make sense of it – it was all so scary. And then, "Right! We've got *three minutes* and we've got to make a decision!"

We still weren't sure when the stroke actually happened, but we had to make this *huge* decision right then! Max said, "Well, if it's going to help, give it to me!"

So, they gave him the drug. And the next day he had a massive bleed in his brain.

We can't help wondering: Did we cause the bleed by using the drug? If we'd waited, maybe he could've had an operation to clear the blocked artery.

But then again, if we *hadn't* used it and Max had had the bleed anyway, then we'd have been forever wishing, "*If only* we'd used it ..."

So, really, we never got a final answer. It was as if he'd had two attacks, and the second one almost completely wiped out the right side of his brain. The doctor called it a "massive, very dense stroke."

GRAPEVINE: What's been the biggest change for you since then, Max?

MAX: Becoming dependent. I've been an independent person all my life. And now, being dependent for pretty well everything ... that's the biggest change. And the hardest to accept.

GRAPEVINE: And for you, Lynda?

LYNDA: *Everything* about life has changed ...

MAX: ... from the most intimate to the most everyday. *Every* part of life.

LYNDA: It impacts relationships. With our kids and grandkids – the things we're able to do with and for them. With our friends. It impacts financially – it finished our employment. It impacts the way we live in our home. It's shattered many of our dreams and hopes for the future. It impacts our social life ... our comings and goings...our leisure time. It even impacts what we eat and the way we eat. Everything!

GRAPEVINE: Are you improving Max, or getting worse? Or is your condition static?

MAX: Well, I don't think I'm getting worse. But I can't see I'm getting better either. There are certain things ... when I look back ... In hospital I was in a wheelchair. Now I can walk and get around a little bit. Not well, but certainly better than in a wheelchair. So, in one sense, I've improved. I go to the gym and that helps me ... hugely.

GRAPEVINE: In terms of personal acceptance? Are you getting more depressed and frustrated as time passes, or less?

MAX: I've read some very good books for people who've had trauma. And they've helped me ... accept it all. I don't think

I'll ever accept it fully, but I do think I'm accepting it better each day. And being ... what's the word? ... content! Being content to look at the little positive things that I'd never have thought about before.

LYNDA: We had no warning. The day before the stroke, Max had been rolling around on the floor with grandchildren – tossing them up in the air. Next morning, that was utterly gone. It felt like we were suddenly just dumped into this black hole, with steep sides, very deep, no way out. There was a glimmer at the top where we knew the rest of the world still carried on – but without us.

Sometimes people would come down into the pit, just to hold our hands and be with us. Other folk would sometimes look down from the top and say things that I'm sure were meant to be encouraging, like: "You've still got such a lot to be thankful for ..."

I learned a lot about visiting sick people in those 10 weeks that Max was in

hospital. To my shame I now realise that I've sometimes visited in unhelpful ways. I used to see my role as being "to cheer them up a bit" – you know?

One couple in particular, I remember, would come to see us – and in 15 minutes they'd hardly *say* anything. They just came right into this black hole and held our hands. But, when some people came to see us, it felt like they were ... well ... shouting at us from the top: "Cheer up! You know, it could be a lot worse." And I'd feel like screaming back at them, "How could it be worse?"

At that stage Max couldn't walk at all – no left leg, no left arm, couldn't stand or sit unaided, couldn't swallow properly or even open his eyes fully. He'd lost all vision in the left side and much of his cognitive ability.

To be told, brightly, "It could be worse ..." wasn't helpful. And hearing that "God's got a purpose in allowing this ..." or that we must be "going to learn some



amazing things through what's happened ...” was *awful* in those early days.

They all wanted to be kind and loving. But, at that stage, we were very fragile, very vulnerable. And we most appreciated those who just came and said, “This is tough. We’ll sit in the hole with you.”

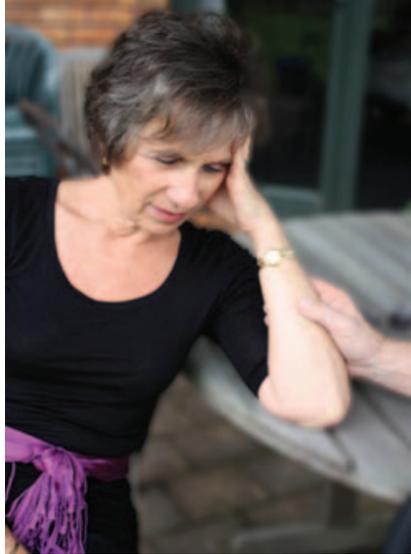
GRAPEVINE: Did you feel well supported during the worst times?

MAX: Mostly. We lost touch with some friends, of course. But others – including some we didn’t really expect to stay in touch – surprisingly *did*. They said, “We want to walk with you through this stuff!” And they *have*.

Something like a stroke ... well, you begin to know who your true friends are. And you value family even more – my kids and wider family. My brother helps a lot with taking me to the gym and visiting my 97-year-old Dad.

LYNDA: One of the things that worried me with visitors was that Max would sometimes say very random or inappropriate things. And I’d feel the need to ‘manage’ this. I’d say, “Oh, Max, you must have been thinking about so-and-so ...” trying to explain away his behaviour. This was so exhausting that I finally decided, “Okay. This, in a way, is a ‘new Max’ – and people who’ve known him have got to decide. They’ll either say, “Well, we’ll all negotiate this new pathway and get to know the ‘new Max’ ...” or “No, this is too hard. We’ll just leave it ...”

One particular friend we’ve had for years committed to keeping in contact. And he rings every Thursday night just to say, “Hi, how’s it going?” He’s really a most consistent, loving, caring person, showing us what walking alongside us in the long haul really means.



GRAPEVINE: Max, are you getting any on-going treatment or therapy for your condition?

MAX: A bit. We’ve been told that my condition won’t improve much. Physically, I go to the gym every week and my walking’s improved a bit.

LYNDA: That helps him keep the right side strong so it can cope with the extra work it’s got to do. And we go to rehab clinic at the hospital every three months to be assessed.

We found in the early months that we couldn’t live our life from one hospital visit to another – from doctor-visit to clinic-appointment to rehab-appointment. You have to make a choice. The easiest thing would be for us to just sit in our lounge and do nothing; but we didn’t want that. Or, there’s the hard way of constant rehab, rehab, therapy, therapy. We’ve chosen a middle road.

GRAPEVINE: How about you, Lynda? Are you getting support to ensure you have the stamina to keep going?

LYNDA: This is an area that's been really difficult for us. I'm given some respite time – but that's actually been hard for Max. We've always done everything together. So if I feel I need to go away for a couple of days' break, it hurts him – being left behind. But it also hurts that he's 'the cause' of my needing to get away. He'd love to just look after himself for those days – but he needs help dressing, showering, meal preparation, all of that.

GRAPEVINE: Have you talked to each other about these difficulties, about how hard it is to accept what's happened? I mean, you've gone from being community leaders to being practically refugees in your home ...

LYNDA: Well, we tip-toe around that a bit. Very early on ... probably *too* early on ... I expressed my grief about some of these things to Max. And, generally, it ended up being fairly painful. He'd begin to feel guilty ... and I'd be trying to say, "No it's not your fault." So sometimes just trying to *talk* about it can accentuate the pain.

I likened it this way: Max had had the stroke *physically*, but it felt like I suffered it *emotionally*. It's hard for Max, because it seems to him that I can still live my life 'as usual'. He'll sometimes say, "Your life is like it always was!" – because I can still go out and have a cup of coffee with a friend or work in the garden if I want to. But the stroke is *never* out of my mind. I never see the world without that shadow.

We're coming to terms now, slowly, with the idea that we need to move into town sooner than we'd planned so Max can have a little more independence. In the country, as we are, we can't go anywhere without a car. We have family and good friends close by, and there are

some lovely folk just across from us who'll come over at the drop-of-a-hat. But I'm reluctant to ask for too much help.

Another thing about a stroke is the way it robs you of initiative. It's wiped a lot of Max's motivation to do or try things. I noticed at occupational therapy, for example, they'd suggest, "Here's something you could do ...". And Max would say, "Yes, I'll do that." The intention's good – but it probably won't happen. So then I face a dilemma: do I keep on suggesting it? Because that then leaves me with a difficult role: wife/care-giver/motivator/promoter ... NAGGER!

Just *saying* this sounds like I'm a thoroughly negative person who doesn't believe anything will ever work. But I don't really think I am. It's not cynicism – it's realism!

GRAPEVINE: Your house seems to be well designed for a disabled person ...

LYNDA: We're grateful for that. It's single-storey, internal garage – no steps anywhere. We had to have the bathroom modified.

After a stroke, it feels like you've had a home invasion – at the start particularly. You've got a commode ... you've got a chair-raiser, a bed-lever, a shower-chair ... and of course there's the wheelchair ... and rails. And then there's the invasion of people you don't know – who came in twice a day at the beginning to wash and shower and change Max. And while we're very grateful for what they do – it does feel like your home's no longer your own space.

Max couldn't read when he first came home from hospital. He could only read the last few words to the right of every line. He'd lost vision on the left side in both eyes. His brain told him that there was nothing there.



Is there hope for those living with the effects of stroke? Increasingly clinicians and specialists are saying “Yes!” The brain is now better understood, and is being revealed as far more adaptable and able to repair itself – given the right conditions – than was earlier believed.

In an inspirational book *‘My Stroke of Insight’*, brain scientist Jill Bolte Taylor describes her complete recovery from a massive left-hemisphere stroke that left her speechless and hardly capable of movement, unaware even where her body began and ended. During her long recovery, these were some of the insights she gained:

- I am not stupid, I am wounded. Please respect me.
- Come close, speak slowly, enunciate clearly.
- Make eye contact with me. I am in here. Come and find me. Encourage me.
- Stimulate my brain when I have any energy to learn, but know that a small amount of activity may soon wear me out.
- Introduce me to the world kinaesthetically. Let me feel everything. (I am a child again.)
- Ask me multi-choice questions. Avoid yes/no questions.
- Break all learning down into smaller steps of action.
- Focus on what I can do – not bemoaning what I can't.
- Please don't finish my sentences for me or fill in the words I can't find. My brain needs to work.
- Love me for who I am today – don't hold me to being the person I was before.

This left-hand/right-hand thing's really quite weird. One day in hospital he asked me, "Who've they put in bed with me?" I said, "There's nobody in bed, only you." "Yes there is!" he insisted. "There's this body in here with me." I said, "No, there's just you!" "But if I go like this," he said, rubbing his left side, "I can feel this other body in here!" His brain wouldn't acknowledge it was *him!*

He'd eat food from the right side of his plate but leave the left side. When he was reading a book he'd read the right side of the page only. I'd encourage him, "Read it all out loud to me ..." and he'd read just the right-hand end of the lines, even though it didn't make sense.

He's now learned to scan right across – so there's been improvement. But if he's tired he'll still sometimes leave food on the left side of the plate.

When we first came home and Max tried manoeuvring around the house, he'd often start something but not finish it. He'd turn a light on – never turn it off. Turn a tap on – never turn it off. He'd open a door – never close it. And he was the one in our family who'd always tell everyone else to turn lights and taps off!

Sometimes he still forgets. But he's more focused now. He's learned to finish those things – turn off lights, close doors, and so on.

Early on I read several books aloud to Max. They were books on suffering – like *'When God Doesn't Make Sense'* and *'Disappointed with God'* – books that some might say were rather bleak. But it's interesting: I *wanted* to read books that talked about grief and disappointment. They gave us hope and courage. I didn't want books that aimed to 'cheer me up'.



I realise that some people want you to be positive – they want to 'fix' everything, to make it better. But there are some situations where that just doesn't work.

GRAPEVINE: Is Max still the man you married?

LYNDA: In the days after the stroke he *seemed* like a different person. It's hard to say this, but I felt in the hospital as if my husband died – and they whisked in somebody else that looked similar and said, "Look, here's another one that's pretty much the same. So take him home!"

That's not easy for Max. I know it hurts him. But I guess when parts of your brain have been destroyed you don't know that they were once there – so it *must* be hard to understand! And sometimes I feel a bit like his *mum* rather than his *wife*. It's funny – it's not the physical things so

much, the fact that he can't do the outside jobs or drive the car. It's more the loss of some of the person who was.

GRAPEVINE: Do you feel you're still the same man you've always been, Max?

MAX: Well, inside I feel the same. And I'm disappointed when it proves I'm not. I used to love doing physical things – running, tramping, playing games. And when I find I can't do that, I feel very disappointed. I feel like I *could* do them ... I just ... *can't!*

I'm reliant on Lynda now. I can't go anywhere or do anything without her, really. And that's hard to accept.

GRAPEVINE: Have you learned anything that might help others living with a stroke?

LYNDA: Max's emotions are closer to the surface now. Tears and frustrations come easily. Sometimes things have been said or done that are quite hurtful, followed by



remorse. So I guess it helps to remember that when this stuff happens it's *the stroke* – not the person – that's causing the heartache.

When life throws you something unexpected, you have to dig deep and discover reserves and strengths you mightn't have needed before. When we left the hospital I thought I could be another Florence Nightingale! Well, I've found I'm not. But I've done things I hadn't done before and didn't think I could!

Max used to excel at things like problem solving, decision-making, planning, understanding financial stuff. He struggles with those things now, and I do most of that.

I'd love to think that what we're learning in the tough times could be of help to somebody else living with sudden trauma. I know I've learned to '*live in this moment*' more – and find strength enough for it. I've learned I'm *not* alone, even though I sometimes feel lonely in the situation. I've learned to be gentle with myself and to find ways to 'restore my soul'. And I've learned to find joy again.

I'm learning that sometimes we have to re-define love. Max and I didn't choose this chapter in our lives. And often it's really hard. But we can still choose *how* we live it ...

CHECK OUT WWW.STROKE.ORG.NZ FOR INFO ON STROKE SUPPORT AND REHABILITATION IN NEW ZEALAND. ASK YOUR LOCAL BOOKSELLER FOR 'MY STROKE OF INSIGHT' BY JILL BOLTE TAYLOR.



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HAVE YOUR SAY!**



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