Submission to the Senate Inquiry into Palliative Care

Kim McCartney and Gary Coleman

My Background

I was a land development officer with the Ballarat water authority when in late 2009 I was diagnosed with brain cancer. My partner Gary Coleman who was a truck driver is now my full-time carer.

I had two episodes of surgery at the Royal Melbourne Hospital which confirmed that my brain tumour could not be totally removed or cured. Since that time I have received Palliative Care (PC).

How I feel physically is a 'day to day proposition'. However I am not in any pain currently, although I suffer from short term memory loss, and even when I write something down immediately I may get it wrong e.g. transpose numbers or leave out letters. I also have some loss of peripheral vision, and am on one medication- dilantrin- to prevent seizures.

Despite rejecting it previously, I have recently decided to undergo further surgery – I have been assured it will not be painful or require rehabilitation or further treatment. It will not cure me but give me a few more months of life, which after discussion with my family, I have decided I would like. It's not for survival but for more time. I'm feeling fine, so there's no need to turn my back on a good life. I'll do the dance another time and see what happens.

Since my initial diagnosis Gary and I have been willing to share our PC experiences with other families, carers and the medical profession. As well as this submission, we have recorded several interviews and programs, including one which was broadcast on ABC RN the National Interest.

Attitude of doctors

When I'd had my first operation down at the Royal Melbourne, and they told me that I had a tumour which couldn't be totally removed, surgically, or cured with chemotherapy, or zapped with radiotherapy... I remember saying to the surgeon at the time, 'Can I see somebody from palliative care, please?' - not because I was ready to die, but because at that stage I've realised, 'Well there's no exit door here so it doesn't matter how many times they operate on me or zap me or what they pump into me, they're not going to cure me. We'd better start facing facts and come to some form of acceptance about this'.

So therefore I wanted to explore the options of what is going to happen. What sort of support have I got? Am I going to have a horrible, nasty death? Am I going to be in pain? That’s what frightened me I wanted to know how and if I could make this journey comfortably.

The response of the surgeons and oncologist at that early stage was that they almost held a cross up at me and went 'Don't use the P-word', which didn’t help me very much.

They didn't want to know about it. They were more 'Come on, you can't give up that easily'. Which didn't sit well with me because all I wanted to do was ensure that when I did die, I wasn't going to suffer. That's really all I wanted to find out.

They acted as if I'd already raised the white flag and started to curl up my toes, and then they said - 'No, no, we don't have to think about that, there are other options here that we can do to you'.

Subsequently I've had conversations with my oncologist about PC, and she also goes to me, 'Kim, you're doing fine.'... , 'We've got options, , if it(the tumour) re-presents, we can operate again, you've still got a couple of doses of chemo up your sleeve and you've still got a few sessions of radiotherapy, we can zap you again... we can still keep going'.

I said to her: ''Yes I know I'm doing fine, but you fail to understand' 'I'm not crossing those hurdles. I'm not crossing those hurdles until such a time that I need to. Then I'll sit with my family to discuss those options'.

I'm happy to keep on living, but I'm not going to kill myself trying to stay alive. Sometimes the medical fraternity can't understand that.

How Palliative Care helped my partner/carer and me

Gary Coleman: Getting in touch with PC made a hell of a lot of difference .We were given all these pills and didn't know anything about them, and PC helped us break down these big, long words for pills down to just what we knew them to be: painkillers, nausea pills, things like that. When Kim first came out, she couldn't walk very far, so they gave us lot of help around the house with things like a wheelchair and getting paperwork and all sorts of things sorted out so we could get on with living.

Currently we get a phone call once a fortnight from the Ballarat Hospice, just asking if we need anything, if things are going well and Bill from PC drops in once a month when he's got a bit of time, all thanks to him, because he's the one that's been the mainstay with us.

Kim McCartney: PC presented us with things that we needed then, that they thought would be helpful, and then as we went along also gave us a bit of a heads up on what other things were available for us.

Having the comfort of their 24 hour number if things turned pear-shaped in a hurry, you know someone will be at your house quickly was and is a comfort for both of us.

Over time you get to know the nurses that are associated with the PC service, and so you're talking to somebody who you've met, who you know, who sat with you, who's had a cup of tea with you, who's answered your questions and so you feel comfortable talking to those people. It's not like you're talking to a nurse, you're talking to Liz, or Julie, or Bill. We could not ask for better support.

The good part about having palliative care is that they are actually outside your personal circle. So, they're not emotionally involved.

Friends, family are all personally involved and they tend to think and say: 'You have to fight this, you have to do this, and you have to do that'. When I was diagnosed, a good friend said 'Oh, this is shocking. Why you? This isn't fair’, and I said, 'Well if not me, who? You pick somebody else that you know that you would prefer to have what I've got.' He just looked at me and I said, 'It's not a personal thing. 'You don't get to pick and choose who gets it.

The bottom line is, if you can accept that you are going to die, and then you do get the chance to make better choices, to make better decisions.

I still consider myself exactly the same as everybody else I know. OK, so I've had the tap on the shoulder and been told, 'Yes, you are mortal and you are going to die'. I don't know when that is but has anyone else been given the heads-up on a time and a date? All that's happened to me is I've had confirmation of what I already knew.

Help and understanding for carers

Kim: When I was first diagnosed, Gary all of a sudden found himself in the position of being my carer. He had no medical background, but I'm very, fortunate that he was very domesticated, I thank his mum for that -it was a blessing.

But just as we've discovered, there must be so many people out there, who are all of a sudden thrown in the deep end. They don't understand what's going on with the illness and, they're not domesticated but all of a sudden have had to take on the full domestic duties as well; it can be daunting in itself if you don't know how to cook or which button to push on the washing machine.

If your carers are all of a sudden thrust into the pressure of not only caring for a loved one who may possibly have a terminal illness, but all these things, all these other roles, they could just crumble-where does that leave your patient? Where does that leave the relationship?

That's an important part that's being missed in palliative care – it is about making the journey for the patient comfortable, but that would be so much easier if the carers had the back-up, the knowledge, and the training, so they don't feel like they're paddling upstream on their own.

In the early days, of course the phone didn't stop ringing and people didn't stop coming around, and they were all very caring. They’d ask 'How's Kim? And to me 'How are you, Kim? No-one said, 'How are you holding up, Gary?

Gary- I felt **s**hit-scared. I haven't got any medical background, apart from the normal stuff you learn at work. But the knowledge that any minute she could go, I'm going, 'Well, where do I go?' But between myself and Kim and Bill (the PC service) helped me to start with to get my own head around everything that was going on and then I could get my head around living with Kim and keeping it up and just keep going.

Home or hospice care?

Kim: Gandarra is our hospice place, up in Ballarat, and when I was first diagnosed... my automatic reaction was 'Oh well, I'll end up in Gandarra: I hope it doesn't hurt'. Now, having been given options I understand that I can stay at home. I would much prefer to die at home, because I want to be able to go outside and have a coffee when I want to; I want to be able to sit up and watch television until 2 o'clock in the morning if I want to. All those things that you cannot do in places like hostels and nursing homes and things like that. So, I now want to die at home, and I have no fear about doing that at all.

My advice to those living with someone receiving palliative care

A lot of patience, a lot of listening, a load of trust; if you can’t get these balanced it will be 10 times harder to cope and care.

You might think you know what’s best for them (and sometimes you do), but you have to listen carefully so you’re aware of what they’re capable of. It’s a lot of give and take to balance out what they should do and what they can do.

Normal things may no longer be possible- your memory may go on lots of little things or worse on big things like what the doctor is telling you, so be prepared and take someone with you to take a note of what’s happening and what you have to do

If you're the patient you have to be clear on what you can or can't do- be honest and just say no when you mean it. They have to be able to trust you on everything.

Until I'm dead please treat me as if I'm alive.

Don't tell me to fight it

The doctors have told me what I've got is unbeatable, and I've accepted it so it's frustrating, putting pressure on me to fight a fight I could not possibly win. Once you accept PC you don't need to be told you can beat it, and it doesn't seem that bad, acceptance for me has been how I've dealt with it. But it can change: I'd had two operations and then went for palliative care, then decided on some more treatment to extend my time. I got through it relatively well, and when I went back for my specialist check up recently, I decided to have another operation which will give me another 6 months. But I have said that's it.

As told to Megan Stoyles

Palliative Care Victoria

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