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Transcript of an edited interview with

Graham and Helen Bullock

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NOTE TO READER

Readers of this oral history transcript should bear in mind that it is verbatim and as such reflects the informal, colloquial style that is inherent in oral histories. The State Library of Western Australia is not responsible for the factual accuracy of this oral history, or for the views expressed herein.

INTRO: Death. It's the most inevitable part of life. Some might say it's the only guarantee. But it's also a topic that many people shy away from because it makes us feel uncomfortable, scared or upset. It's often swept under the rug, not acknowledged or talked about, until of course, we come face-to-face with it ourselves. We hope to end this taboo through a series of interviews with many different people from all over Western Australia. We talk to ordinary people about their views on the grief, loss, love and celebration that *is* death and dying. This is a conversation on death.

GRAHAM: My name's Graham Bullock. I'm 68 years old. I was born in England in 1954. And then we moved out to here with a family in 1991.

HELEN: I'm Helen Bullock. I am 67 years old. I was born in England in Stoke-on-Trent, Staffordshire. I married Graham in 1975 and we had four children and then we decided we'd emigrate. And we've been here, like Graham said, since 1991. I've had various jobs and then I went into nursing later in life. I took an aged care course and then managed to get a scholarship through the government to do my enrolled nursing. Then I worked at Royal Perth [Hospital] up until I was 62.

GRAHAM: Fortunately, I decided after a conversation with Helen, to retire just after 60. And I say fortunately because by the time I was 65, that was when I was struck down with MND or that was when I was first diagnosed. Since then, it's just been life in a wheelchair, with Helen, my carer, my only carer.

RITA: So, Helen, when Graham got the MND, motor neuron disease diagnosis, what did that feel like for you, with your nursing background, knowing what that might mean?

HELEN: Well, I just couldn't believe it at first. It was just devastating. To be honest, even though I knew what motor neurons [disease] was, I *didn't* know the complexities of it. We were told originally, by the neurologist who diagnosed Graham, that [he] would [have] two to three years life [left]. And I was [thinking], God, what do we do? What do we do from here? It was frightening, wasn't it?

GRAHAM: Well, it was a bit of a shock. But we realised there was something seriously wrong. The original examination lasted for about an hour. And this doctor stripped me right down to the underpants and he just checked every part of my body and stared into my eyes for a long time.

HELEN: So, the MRI was of the head, the brain, the full torso and like this, all down to the spine. Obviously then we had to go back, and it was a hundred percent. I think it was at the end of May then, wasn't it?

GRAHAM: It was May the 31st. Yeah. It was a Friday afternoon. It was a beautiful day. We were on our way to a rugby game that night. When we found out Helen was quite devastated [and] I was shocked, obviously. Helen wanted to go home. I said, no, we'll carry on planning to do what we were going to do. We decided not to tell anybody for the time being. I don't know why we decided that.

HELEN: I think because we wanted to tell the children...

GRAHAM: Well, we were always going to tell the children first, whatever happens.

HELEN: I think we just needed to come to terms with it ourselves.

GRAHAM: As much as anything else, probably, yeah.

HELEN: I noticed his walking was a bit different, his gait. So, I thought, well what's this, [and then] it started to get a little worse. You were tripping and getting quite tired as well, after you'd been walking anywhere.

RITA: Helen, for people who may not know what and how the disease progresses, from your nursing background, [could you] give us the bare bones of what happens when somebody has MND?

HELEN: Well, your actual neurons for some reason die. It doesn't send the electric charge to the muscle to work.

RITA: So, these are neurons in the brain?

HELEN: Yes. There's two, there's an upper one and then there's the one which more or less goes into the spinal cord. There's a frontal one and the lower one. It is like your neurons somehow die, they stop charging to the muscle and then eventually the muscle just wastes away. So that causes the leg muscles to get very heavy and dead and you can't move them. That's obviously [what happened with] Graham, [it] started in the toes and it seems as if it's moved up and now it's starting in the arms and your fingers, up to your shoulders a little bit, isn't it?

GRAHAM: Well, it's difficult to lift my arms. Yeah.

HELEN: But there are different kinds. Yours was diagnosed as...

GRAHAM: PMA.

HELEN: Yeah. Primary or...

GRAHAM: Progressive.

HELEN: Muscular atrophy, which we have been led to believe is a slower form [of MND]. We weren't quite sure because you don't know what's going to happen and you don't know how quick it's going to happen. I mean, like Graham said, we've reached now almost three years and even though the first year was pretty easy going and the second wasn't too bad, it gets harder. Since about last April you haven't been able to walk, but you were able to perhaps stand just a tiny bit; but now I have to either use a hoist or a slide board because you can't move at all. Only like *that*, you know, just from side to side.

GRAHAM: Yeah. I started losing the use of my legs first. Now I'm having problems with my hands and arms. So, although I did accept it straight away and I realised it couldn't possibly be anything else, when I saw all the people with it, I thought maybe they're wrong, but no, it turns out [they were] right.

RITA: Helen, what about you? How did you get yourself to that point where [you realised] there is no coming back from this?

HELEN: We felt like we'd just been handed this death sentence. I think I was just frightened how quick it was going to all happen.

GRAHAM: Which it can do in some cases.

HELEN: It can. So, then I just thought, well, we'll just cope with what's happening and try and live as much as we can, normally, and then just manage each stage when it happens. That's what I've tried to do and we've both tried to do, really, haven't we? I mean, sometimes it's hard. Some days things don't work, but we just find other ways around it to cope with it. That's what we had to do. You know, it's not something that we can just give back. We've just had to get on with it. I think right from the start, even before seeing the second neurologist, we had contacted the Motor Neurons [Disease] Association and they sent a support worker out and she talked to us. Then at least [we had] the support, to know somebody was at least behind you, who knew what was going on.

RITA: Graham, how important was it that Helen picked up that phone and spoke to the support group that allowed you to get some perspective about where you might be heading?

GRAHAM: Well, that's right. It was a big relief. It was a weight off the shoulders if you like, knowing that you were in touch with somebody else or a group of people who were familiar with what's going on and what's going to happen to you. That was good to know that. Then of course we started going to these functions and we met all these other people. That was when I realised what could possibly happen to me in a very short space of time.

RITA: I'm going to take you back to last year, which is when I met you both, to WA's decision to legalise voluntary assisted dying. You came across very strongly, Graham, when people were debating the pros and cons of having such a choice. I just want to talk a little bit about that and what your opinion is of legalising assisted death?

GRAHAM: I was all for it at the time and I'm still even more all for it now, more so now because reading of other people's issues, not particularly in Australia, [but] in England, for example, you know. Every day I'm reading, it's actually on Facebook, I'm not ashamed to say, there's quite a few support groups on Facebook, and on some of them, people are just suffering needlessly in other parts of the world. In England in particular, where they don't have this choice. What the actual victims or patients, whatever you want to call them, are going through and what their carers are going through, it's just horrible. It gets to the point where you have to walk away from it sometimes because it's that distressing.

So that's why really, I'm all for it. I'm just so grateful that [in] six months, 12 months, whenever, that I will have a choice, because it's not just a patient who suffers, it's the family as well. It's a dreadful situation to be in. To have that choice is really heart-warming, if you like knowing that you don't have to suffer. Having said that, it's not just for MND, it's for cancer patients as well. People just should not be allowed to suffer like they do, like we've made them to.

HELEN: I actually used to work on the chemotherapy ward and hematology and everything. To be honest, I do feel strongly about euthanasia, and I do feel people should have the choice. Especially when they have got a terminal illness or if they've got an illness that can be resolved, but they're in an awful lot of pain, or they can't do anything about it. I think when they brought the voluntary assisted dying [in], there are things in place and you can be interviewed by a doctor to make sure that the decision is right. You're not just wanting to commit suicide, take your own life, but there is a good reason. I mean, if your life gets to the point where there is no pleasure in it and you're not enjoying your life, you're full of pain or you can't move. It does concern me, for Graham at the moment. We do have bad things, but we do still have a lot of good things happening, but I'd hate it to be that it's all bad for him. So even though I don't want to lose Graham, I know it's inevitable [that] it's going to happen. I do think there is a place for it. I don't think everybody should go for it obviously, but I think if people are suffering, yes, I think the choice should be there.

GRAHAM: We were both actually brought up as Roman Catholics. And if there's one thing you learn being a Roman Catholic, it's that one day you're going to die, and they more or less teach from the day you start school. They actually start preparing you for it. So probably the only place it is spoken about is in the Church and it does need to be brought out into society more. It shouldn't hurt people, like Helen says, it's something that's going to happen to all of us. And as long as you're prepared for it...

It's good being in a position where, like myself, I know it's around the corner or it's just up the road a bit. That makes it easier because you enjoy everything that's available to you and you make the most of it. With a family and that, although we are a close family, we've got four children and they've all got children. We were always pretty close, but since this has happened, we've become even closer if you can imagine that. Which is a good thing.

RITA: Did you feel a responsibility, both of you, to protect the kids and the grandkids from the reality of the situation? How did you work all of that out?

GRAHAM: Well, we said we weren't going to tell anybody. I was diagnosed on the Friday and we said, let's just sit back and think about [this], see how we approach it. But by the Sunday morning, two days later, we thought, oh gosh, you know, we better tell them. We better let them know. But regarding the grandchildren, we didn't say anything to them. I think the parents eventually told them over time, because they range in age from 30 down to... well, we've got one now that's five months old.

RITA: Helen, what's it been like for you to be Graham's partner at his side, listening to that diagnosis and then becoming overnight his primary carer?

HELEN: Well, the first 12 months weren't so bad. I kept thinking when are things going to change? It's just gone gradually. I said I was more than happy just to try and manage and cope and look after him at home. I still stick by that, even though it's getting harder now, [but] I don't want Graham to go into a home as long as I'm physically able and we can get help coming in, we'll try and keep him at home. It's only until, really these last couple of months, [that] I've started to find things are getting quite heavy and a little bit more difficult with the showering and the personal care. So, we've actually started to get some carers in, only twice a fortnight, just to give me a break. And even just that has been quite a bit of a relief. It is hard and I get tired and we just want you to be as comfortable as possible.

RITA: Graham, how do you cope with that?

GRAHAM: With Helen looking after me or...?

HELEN: Be careful what you say!

GRAHAM: No, look, she does a great job. There's no two ways about it, but I do feel that it would be nice if we did have more help. To be honest, we just don't have enough help at the moment, although we are coping alright. Look, I spend a lot of time in the chair, which I probably would do anyway, but it would be nice if Helen could have a weekend off, for example, or even just a couple of days off. I mean all she gets now is two hours a fortnight, doesn't she?

HELEN: Which is a bit laughable, isn't it?

GRAHAM: Yeah. She gets two hours a fortnight off when somebody comes in and sits with me. Otherwise, she goes for a swim on her own in the morning or she'll go for a walk and do some exercises. So, she'll have time to clear her head and put me on the backburner for the time being. Just have some time for herself. But I do feel that we are getting to the point where we do need a little bit more assistance.

RITA: And in terms of your relationship, are you stronger now than you were [before the diagnosis]?

HELEN: Oh, I think we are.

GRAHAM: Oh, definitely. Yeah. Well, we've been together 47 years...

HELEN: I think we've been very lucky. We've always had a really good relationship. We've always felt a lot of love, haven't we?

GRAHAM: Definitely, and the love's matured over the years, hasn't it?

HELEN: I think sometimes it's a very hard thing because Graham's needs are... I've had to take over his personal needs, and it's a good job that we are close. Because it's all his dignity taken away. I think probably because I have done nursing I could accept that, but it was hard for Graham to accept [I would] attend to some of his personal things. Because he

can't do it himself. Where it's been a lot for you to swallow, hasn't it? Whereas for me, I could accept it and I don't think anything, my love or my relationship with Graham, it hasn't destroyed any of that. I think mentally sometimes I've had to start finding ways to cope. At the moment you found us on a good month, because in March I was going through quite a... Everything was moving, and I was in a bad space then.

RITA: Graham, do you feel that there is a clock that's ticking?

GRAHAM: Look, to be honest, it's ticking but it's ticking very slowly. At the moment, I feel like I could go on like this for many more years to come. If I was going to be honest with myself, I really wouldn't want to be going on like this for years and years to come. It does feel like it's progressing slowly, but not to the point where I'm not concerned about it.

HELEN: Graham's breathing is quite good. But [people with MND] start making secretions, like fixed secretions, and can't swallow and I do watch out for things like that, anytime the food goes the wrong way, I think, oh no. I just don't want Graham to suffer.

GRAHAM: You know, I do love eating. There's no two ways about it. And Helen's a demon in the kitchen, especially with Italian food. Now, if it comes to the point where I've got to have a PEG inserted in my stomach and I've got to have all my food mushed up and that, it's not something I'm looking forward to, to be honest, it's not something I think I'd really want to put up with. If I had to have a breathing tube put in there... Look, I'm almost 68 years old. And if the end comes soon, then there's no two ways about it. These support groups I was telling you about earlier, you read on there about people [who are] 29, 30, 35 [being diagnosed]. And that's just dreadful. You know, I've had my shot and we've had a great life and [I think] okay, so it's my turn. Don't feed me through a tube and don't tell me to breathe.

HELEN: I was actually thinking last year, when we'd been to that ABC forum, you'd got these girls in place. Our youngest son, they were expecting another baby. She was born in November. So, we'd got a new baby on the way. You wanted to see your granddaughter. one of our [grandkids], the eldest grandson, turned 18 in January. [So, Graham had] got all these girls [around him] and this year, you've not said anything at all [about euthanasia]. I don't know whether you're just glad to wake up each day, I'm not quite sure. But you've not actually made any goals, have you? Oh, you have, because you reached 68 this week and that was what your father was [when he died], wasn't he?

GRAHAM: Well, no, it was almost 68 when he passed away. Yeah. So, I've passed his age, but I'll just set different goals now. I'm just looking forward to Willow, having her sit on my knee. That's our youngest granddaughter. And perhaps get to see River play football, play soccer. Yeah, because he is going to be playing soccer. So, it's just like life anyway, isn't it? You just reach a goal and then you set yourself another one. That's how it's been our whole lives. We're always surrounded by family. And it's always about eating, isn't it? That's the Italian in us. We just love eating and talking and [the] occasional drinking. It could be a lot worse, Rita, it could be a lot worse than what it is.

OUTRO: Thanks for listening. This interview was recorded on the lands of the Whadjuk Nyungar people, and we pay our respect to their Elders, past, present and emerging. This

oral history collection was commissioned by the State Library of Western Australia and produced by Luisa Mitchell from the Centre for Stories. Narration by Luisa Mitchell, editing by Mason Vellios and special thanks to executive producer and interviewer, Rita Alfred-Saggar.

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