

## **PUMPHEAD – TRANSCRIPT**

### **00.00.20 To Know the Dark**

To go in the dark with a light is to know the light.  
To know the dark, go dark. Go without sight,  
and find that the dark, too, blooms and sings,  
and is traveled by dark feet and dark wings

- Wendell Berry

### **00.00.58 LISETTE'S DREAM:**

I'm standing on the corner and the street disappeared. I cannot simply... It's impossible. I have to take another street and I didn't know what to do, and I simply don't know where I am. What's happening here?

I knew after this heart surgery that something changed and I didn't know what. They think, I fixed you. Thank God, I'm extremely grateful for that.

Something else takes over. So much more is stirred up.

### **00.02.14 ANDREW - NARRATION:**

This is my beautiful city of Canberra. My family lives here along with a strong circle of friends. For 27 years, I ran cinemas in the city and built a business in the film industry and made documentary films whenever I had the chance.

Then suddenly everything changed.

On the 5th of December 2011, I had open-heart surgery. The surgery saved my life, but it also affected every part of my life.

My physical recovery was rapid and I started exercising again. I returned to work, but things weren't right. Everything was a struggle. I felt disoriented. I couldn't cope with everyday life. At first, we thought it was shock and the anaesthetic, but everything got worse as time went by. I saw professionals, but couldn't find the help that I felt I needed. And we were all affected, my family and my friends. We were all struggling to cope with the new person who was me.

Eventually, a friend searched on the internet and found academic papers galore about the after-effects of open-heart surgery. Some of the studies even dated back to the 1960s, when the surgery first became commonplace.

Then questions arose. With all this literature, why is the subject still not

discussed today with patients? Why are patients left to find out about it by themselves? And what exactly is the problem anyway, and what's the prognosis?

We found a scientific name – post-perfusion syndrome - but some people, particularly patients, liked to call it pumphead, the term that seems to have started as locker room slang among professionals referring to the heart-lung pump that keeps patients alive during the surgery.

A couple of years after my surgery, I happened to come across an organisation in Melbourne called the Australian Centre for Heart Health. The Centre seemed to specialise in precisely what we were concerned about. I made contact and went to see them, and what they had to say hit me hard.

#### **00.04.54 AUSTRALIAN CENTRE FOR HEART HEALTH montage**

**Dr Barbara Murphy:** For heart patients, the emotional recovery is huge and it often goes undetected, unrecognised, and not supported.

**Dr Rosemary Higgins:** We're getting the right outcomes medically for the patients, but the psychological outcomes are just as important because that's the reason why we keep patients alive - to live their life, not to just be alive.

**Prof Alun Jackson:** As we live longer, as surgical techniques get better, we're living with the consequences for much longer, and so we have to address them properly.

**Dr Barbara Murphy:** The relationship between heart surgery and the emotional or psychological wellbeing of patients isn't fully well understood. Is it related to the bypass pump? Is it related to the medications? Is it related to the disease process itself? Is it related to some other factors that have occurred during the surgery or the procedure?

**Prof Alun Jackson:** We have to accept that the legitimacy of the position that there are psychological, emotional consequences.

**Dr Barbara Murphy:** These procedures are so amazing, they're intricate. I've watched them being performed, and you think, how do they do this? It's extraordinary what they can do, and we've advanced that physical, that technology, so far, and yet a person can be left broken.

**Dr Rosemary Higgins:** They may be very focused on the medical issues, on people's physical capacity, and on keeping them alive - which is a very good thing to be focused on – but there's also the need for once people are kept alive, for them to thrive.

**Dr Barbara Murphy:** We can't categorically say you will experience this or you won't experience that. People seem to go on their own emotional roller-

coaster, and it's very hard to predict exactly what's going to happen for any one patient.

**[Andrew]** What do you call this?

**Dr Rosemary Higgins:** I call it, this reaction, I call it distress. I call it normal.

**Dr Barbara Murphy:** We don't have a really accurate term for this. I keep calling it an emotional roller-coaster because I haven't got a better word for it.

**Dr Rosemary Higgins:** It's a very traumatic experience to get your chest ripped open. That's major.

**Prof Alun Jackson:** The first thing you have to do is to prove to people that it exists, and it exists at a level that means you should do something about it.

**[Andrew - narration]** As we were wrapping up, it all got personal in a way I hadn't been expecting. What they said inspired me to really get serious about making this film.

**[Andrew]** Well, I just wish I had started this three years ago.

**Dr Barbara Murphy:** I know. But I was thinking about that last night too. We couldn't have started this three years ago because you weren't ready to talk about it in the way you are now, and we didn't know: we were amongst the health professionals who didn't fully know about this issue and about how to approach it and address it. We're just beginning, you know, so I guess we're walking along together. Now is the right time.

#### **00.08.19 ANDREW - NARRATION:**

I put information on the internet about the film and arranged to meet a few ex-patients. I soon realised that whatever the medical reason for cardiac surgery, pumphead is a great leveller that seems to have the potential to be there after any form of heart surgery.

Eventually I settled on several patients whose stories intrigued me. We recorded Skype conversations, then moved on to filming. I learned a lot from each of them, as we all tried to make our own way towards understanding and some form of resolution.

#### **00.08.56 PETER GALLAGHER:**

In my lifetime, I've had five open-heart surgeries, starting from the age of 13. So it was in 1985. Through 30 years worth of open-heart surgery and all the cardiologists and all the GPs and all the surgeons, no one had ever mentioned it to me ever.

No one ever has mentioned to me that there might be a need for me to go and see somebody about psychological problems, emotional problems, cognitive problems.

I think the reason why I haven't been given any information - I guess it's a little bit interesting. So because, so when I was 13 and 16, with those surgeries, it could have been a generational thing, you know: people didn't talk about that stuff in the 80s. I don't know. But you know, you're kind of sent home with an A4 sheet of paper with exercises to do and off you went. And I lived in the country, so we didn't have access to cardiologists and rehab back then. And it just wasn't discussed. It was basically stretching exercises.

In 2014, when I left hospital, and while I was there, there seemed to be this ongoing thought-process that I was an expert, so I didn't need to do some things that other people might have to do. And whilst it was kind of said jokingly a bit of the time, I think it kind of became real. It was like, oh, Pete's an expert, so he knows what he's doing. We'll leave him be. And yeah, I don't know, I don't think it's a badge you want to wear really.

Emotionally for me, the journey has been a bit of a roller coaster. In terms of cognitive ability now, I think I do ... I do forget how to do some things. I do start things and forget what I'm doing. And I think that reduction in cognitive ability then ends up having further impacts on you, and that's primarily around confidence.

We used to have lots and lots of dinner parties, and we just don't have them anymore because the whole idea of completing a three-course meal for people fills me with dread. You know, emotionally that can become really draining because you're constantly thinking, you know, what am I going to stuff up next time?

One of the experiences that really made me realise that there was something not going so well for me, that was post-2011 heart surgery. I was looking at a vegetable and for the life of me, I could not think of the name of that vegetable. And I recall getting quite upset, thinking, you know, seriously, it's a vegetable that I buy all the time and it's in the supermarket all the time or in the fridge at home. I should know what this is. And I decided that I was going to stand there and stare at this vegetable till I worked out what it was. And eventually I worked out that it was a zucchini. So in future instances, whenever I had a memory blank, we would call them my "zucchini moments".

**[Andrew - narration]** With Peter's story, it was the anxiety that struck me. Everyone stumbles as Peter does, but this somehow felt different. People with pumphead often seem to zip straight from ordinary forgetfulness to anxiety or panic.

**00.12.50 PETER LYNSKEY:**

The cardiothoracic doctor came in and said, look, you're going to have to sign here. You've been playing up on us and we've had a bit of an event. And we're going to have to rush you through for emergency surgery.

I went through the surgery: they all prepared me, and when I went, I had my wife, my daughter, and waved goodbye and sort of hoped that I'd be seeing them again.

When I came out of the surgery and I was in the recovery section, I basically looked around and physically it was like playing impaled. I was sitting in the bed, unable to move, I didn't have a lot of strength. And all of a sudden, there's that feeling - fairly helpless, actually. And gee, you know, how am I going to get through this? You know, I haven't got any tools, I've never had to deal with this.

I really, you know, I believe that I've sort of gone backwards. I was so fit leading up to that. There was just a complete reversal for me. I was looking around dancing at shadows at every move or everything that actually happened, every tweak to the heart and any sense of pain - where it was really insignificant to the doctors and the like, to me, it was important. Because I had three children still going through school at the time, you know, what am I going to do?

**(Mike Lynskey, Peter's brother)** I was with my brother at my sister's place, and my sister is a nurse. And I mentioned that I was working with you, making the "Pumphead" film. And my brother, it was a Christmas Eve and we were in Melbourne, he became incredibly emotional and he started talking about what had happened to him when he had had his surgery. And he began to cry, and then his wife who was with him, she cried as well. My sister who had had a lot more to do with my brother than me, was astounded to hear all this. It turned out that he, maybe 10 years after he'd had the surgery, couldn't sleep properly at night. He'd get up and have to turn all the lights on in the house. And so it really struck home to me that my sister and I had not been aware of the impact of the surgery on my brother. He was alive and he was getting back to being healthier again, but psychologically he was a mess.

**(Peter Lynskey continues)** The reassurance that I was looking for, Andrew, was that I was going to be okay and that I could go through the normal process of living a normal life, but none of that was forthcoming.

**(Mike Lynskey continues)** I've worked in the public health field most of my life in one way or another, and so I've observed over that long period what can happen - that you think you're doing one thing that's good and then you find there are unexpected and devastating consequences. So I think that human beings are very clever with technology, but we're not so good at understanding the implications for people in real life. And I think in medical procedures, we've devised ways to intervene with human beings in such ways that often it's beyond what a human being can bear.

#### **00.17.04 JESSICA CAUDWELL:**

I'm Jess, I am 21. I work in childcare, so busy, busy doing that. I'm a country girl and around horses and animals and outside and always on the go. I had my open-heart surgery 18 months ago, and I was diagnosed about three months before that. I actually got diagnosed after falling off a horse.

My scar goes from the top of my left shoulder blade all the way down and it comes down to my left ribcage, and there's chest tube scars underneath that as well.

The recovery was initially a lot different to what I thought it was going to be. My nurse said to me one day, she said, "All the nurses fight to look after you because you're the youngest on our ward by about 30 years at the moment." And so I always had a giggle about that, but I met another gentleman who was having surgery with my surgeon on the same day, and what struck me when I met him was just how much older he was than me. And I think that was when it really hit me that okay, yeah, I'm a bit atypical in terms of my age and what I was having done. I think I got that feeling that day that, okay, yeah, this is not maybe as common as what I had thought.

I felt a little bit almost betrayed by my body. I definitely experienced some depression-like symptoms. I was very, very low, very sad, and very, quite angry, I think just at the entire situation, just at my body, and you know, why has this happened to me? And, you know, what did I do to deserve this?

I didn't know what the symptoms were to look out for. So that all came as really a big shock to me when it happened. I wasn't really sure what it was. But it wasn't until quite a few months later that I sort of started to go - hang on, no, this isn't normal. You know, I shouldn't be having panic attacks and I shouldn't be crying in the middle of the night about all of this stuff going through my head.

It's very confronting, and you don't feel like you want to burden people with that. And I know I definitely felt like everyone's done so much for me, and, you know, they've turned their lives upside down for me to be there for me that I don't want to burden them anymore. I don't want to put this on them. This is my problem; I have to deal with it. And so it took me quite a while to say to them, you know what, I think I need help.

**[Andrew - narration]** At the end of our conversation, Jess came out with something I wasn't really expecting: strong statements about language that echoed a lot of my own concerns.

**(Jessica continues)** The term depression is so clinical. I think depression is an actual illness that some people do suffer from. And I think, yes, we have those symptoms and some of those do correlate quite heavily. I think we don't actually have depression though. We just have the symptoms of this big experience that we've gone through. They present the same, but they're not the same. And I think that's what people don't understand. I think there's

quite a lack of understanding of what it actually is that we experience after surgery. You can't just lump us in with another group of people just because it's convenient or because you think it looks the same.

I really love the term pumphhead. It's not a clinical term, but who cares what other people think? Like, that's our name and we can claim that and we can feel good about claiming that, and we should, you know.

#### **00.22.01 ROSEMARY MANGIAMELE:**

**(Andrew - narration)** The potential for carers to experience trauma of their own really became clear to me when I talked with Rosemary Mangiamele. She was the wife of a filmmaker I'd always respected, the late Giorgio Mangiamele. Rosemary talked to me about his time in hospital.

**(Rosemary)** Giorgio, my husband, he had the open-heart surgery. It was quite horrendous really. I'm finding this difficult to explain, but it was an horrendous time, because the morning I went to see Giorgio, he was on the floor and the nurses hadn't been in to see him that morning. So then they had to get him into intensive care.

It was not an easy time really. He was quite shattered by the surgery and because he'd always been very fit and very able and did things, and then suddenly he felt sort of quite debilitated, I think.

**[Andrew - narration]** Interestingly, Rosemary had worked in a Melbourne hospital as an occupational therapist, and had specialised in the care of cardiac patients.

**(Rosemary reads booklet title)** "Occupational Therapy Management of the Cardiac Patient."

**(Andrew - narration continues)** She'd actually co-authored an early booklet on this subject published in the same year that Giorgio's surgery had taken place.

**(Rosemary continues)** It really hit me how severe it was. I mean, perhaps I had been aware, but not as deeply aware. He was trying to write scripts, and he had a friend and they wrote things together. They actually got to a point of submitting one script to Film Victoria where they glued a couple of the pages together because he was suspicious that because it had his name on it, that they wouldn't even look at the script. When he got the script back, it had the pages still glued together, so that reinforced his thinking.

This is one of the few images that I have of Giorgio after his surgery. It was painted by Margaret Cowling. She was going to throw it out because some water had run on it, but I just, I loved it, and I felt it was a bit like tears that had splashed down there. And so yeah, I framed it.

## 00.24.24 DISCUSSION OF CARDIAC REHABILITATION

**(Dr Barbara Murphy)** We know there's a lot of people who've had a heart event, whether it's heart surgery or heart attack, who are not getting the support they need for their emotional recovery and their psychological recovery, whether it's emotional, psychological, cognitive, including anxiety and depression and PTSD. It's a good proportion of people: it could be up to three out of four people. Whilst some of them go to cardiac rehab, and not all of them do - only about 40% of people go to cardiac rehab, and cardiac rehab programs are getting a lot better in dealing with the psychological and psychosocial needs of patients - it's still not providing that individualised support that people often need, and so that's what we want to do. We want to really work with people who need individualised support from someone who's trained and who understands what they're going through. That's the gap that we want to fill. We can provide that, and it's not being provided at the moment.

**(Dr Rosemary Higgins)** There is change. There is change afoot. We're doing a lot of good work in getting health professionals aware of this. We're running networks, we're doing training, we've got resources. We're starting to have a little bit of scratching at the surface and we want to do so much more. We want to improve the lot of patients. The health professionals who do this sort of work with us actually find that their work with patients becomes more meaningful.

**(Prof Alun Jackson)** The point of the Centre is obviously improving the lives of people, but the main role that the Centre performed was researching psychological and behavioural aspects of cardiac disease and has been a world leader in that area. And it's really nice to see that a lot of other researchers have now caught up with that. So a lot of attention is paid to the research.

We then also train the cardiac rehabilitation workforce, interpreting the research to them, ensuring that that then went into best practice in cardiac rehabilitation.

The third dimension that we want to add is to now ourselves provide psychological support to patients, families, and carers.

We're actually talking about adding years onto people's lives, right? So we're talking about increasing greatly the quality of people's lives in that recovery period and preventing second events and subsequent events. We're getting good at fixing people, getting good at the plumbing, getting good at all of that sort of thing, but we're still not good, in the sense, we know what to do, but it's not recognised to the same extent, the need to actually intervene in those areas.

I'm not prepared to have people go on saying that this isn't important. And there are so many people out there who have experienced these issues, I'm

not quite sure why they haven't been harnessed in the past to argue for greater response. And maybe that's where something like this ... (gesture at camera). I mean, our voice is small and we tend to talk to academics and practitioners who read journals and practitioners who we train. And that's why something like this is of really great benefit, because it's talking to that wider group.

#### **00.28.43 PAMELA COHEN:**

**[Andrew - narration]** I went to meet Pamela Cohen, a remarkable figure in the history of cardiac rehabilitation in Australia. In the early 80s, she'd been a driving force in developing a new rehab program with St. Vincent's Hospital in Sydney. This program broke new ground and it's still there flourishing today.

**(Pamela Cohen)** So I started to work in this program, a wonderful program which I'm so proud of really. It's a gold standard program in my opinion. And one of the things that was very important in starting the program was that I wanted patients to have an opportunity to talk with one another. We would have group meetings, which were designed around patients talking about their experience and helping one another with the problems that they were having. And I'm really pleased to say that this model and way of working has continued to this day and this makes it quite different from other rehabilitation programs.

If we take one example, which is an existential example - the existential issue of death anxiety. Now, people who have the traumatic cardiac event, whether it be surgery or heart attack, all have death anxiety. Of course they do. Everyone in the world has death anxiety, but a diagnosis of heart disease or cancer or something like that makes the death anxiety well up like in a volcano and can be absolutely overwhelming. So how can I as a social worker help people with death anxiety? I must say I used to worry about this a great deal. I used to think that perhaps there were some words I could use that would settle people, that would take this awful anxiety away. But once I came to terms with the fact that this is an existential problem, my idea of what I needed to do in these groups changed. So if we have, for example, a discussion about death anxiety in a cardiac rehabilitation group, what we'll have is a discussion about the way people are processing this in their own mind. And the person who's more overwhelmed will listen to the person who's actually handling it quite well and learn from that.

It's quite dramatic what can happen when people share what it's like to recover from something that could have killed you and to be grateful to be alive, to feel like if one more person says to you, "You're lucky to be alive," to feel like you could punch them in the face because you get so sick of hearing it. You know you're lucky to be alive. How does that help you having that said to you over and over again? You've got challenges about being alive. It's more that, than that you're lucky. Chances are you weren't lucky: you were saved by medical skill, in any case.

**(Dr Barbara Murphy)** I've been in situations in the cardiac rehabilitation setting where I've been working with a group of patients. And once you allow the space for patients to acknowledge these emotional changes, the relief in the entire room is palpable because they haven't had a chance to say this before. Invariably, they nudge their partner who might be sitting beside them and say, "Oh, you thought I was going mad, didn't you? And I'm not, this is what is happening and this is expected." And it's an enormous relief once people know that it is part of the recovery process, it isn't out of the ordinary, it is common. It doesn't mean it's going to make it easier to get through it, but just knowing that other people are experiencing it too gives people an enormous sense of hope and of normality.

**(Pamela Cohen)** I decided that it was quite important that I try to influence other people and teach other people about how to be a group worker, how to do this well. And I found in all the teaching programs that I've been engaged in that it's often lack of confidence and lack of knowledge that prevents health professionals working in a therapeutic way with a group. They have fears about this. They have fears that they may open up a can of worms, so to speak, or Pandora's box, some people say, and all sorts of emotions might flood out that they might not know what to do with, and they don't know how to handle these things. I think they often know that it would be a good idea if they were able to let the patients talk to one another and help each other, but they're nervous about it and they don't know how to do it. And it's a professional responsibility of people who run cardiac rehabilitation programs to make sure that their staff know how to do this, because it's alienating for people to be lectured at. They don't want it, they're not interested in it. The information can be delivered in another way.

#### **00.34.14 ANDREW - NARRATION:**

I'd been wanting to find a scientist who could talk about pumphead from direct personal experience. I met Dr Allan Coop, a neuroscientist who was preparing to have major cardiac surgery. He proposed that we run an experiment and film him before his surgery and again a few months after and see what changes, if any, had occurred.

#### **DR ALLAN COOP:**

My cardiologist, while we were discussing what was going to happen to me, said in passing, sort of managed to slide right over it and immediately onto the next subject. But he said in passing something along the lines of "Oh, you may need some sort of psychological medication after the procedure." But it wasn't even as clear as that. And well, that's my memory of it. And I was a bit surprised, like what do you mean, you know? But he'd already moved on to the next subject and so there wasn't really an opportunity to ask him any questions about it.

The whole thing is just so novel that we don't have the language to talk about it. We don't know how to distinguish between the different forms that it takes. It's quite plausible that doctors don't want to talk about it because they actually can't talk about it. Some of the things that the professionals are now able to successfully manipulate are just so far beyond anything that was even conceivable, probably even 20 or 30 years ago. There's undoubtedly going to be a huge lag between the ability, the things we can fix, quote unquote, and the capacity of the mended to deal with the fact that they've been fixed.

### **Two months after surgery:**

**[Andrew]** You said, this is your words now. "The capacity of the mended to deal with the fact that they've been fixed."

**(Allan Coop)** (gasping) Well, there you go. There you go. (gasping) Well, I mean, the thing for me was this moment of driving into Canberra. (gasping) It's okay.

**[Andrew]** I don't want to ...

**(Allan Coop)** No, it's okay. No, it's fine. Because I think that it's important to be able to communicate this. It's just that everything was at once intensely familiar because I've lived in Canberra on and off for 30 or 40 years. But at the same time, it was dramatically different. That point that I've come to when I'm rationalising it is the fact that you are for all intents and purposes dead for the period of time that the procedure occurs. It's not an experience that historically you come back from. Surviving that procedure, you literally are being resurrected.

I have a confession to make, I'm trying to re-invent myself as a digital composer, because I think that that's a nice sort of gentlemanly approach to the last 30 years of my life.

When I went for my first consultation with the surgeon, I noticed that he had lots of flowers and cards arranged all around his office, you know, dozens and dozens and dozens of them, which were presumably from thankful patients, giving their thanks to him for his services. And I thought, well, it would be really nice to do something for this guy because it's been, I mean, it's a cliché, but it's been a journey. So it's this piece which is called "A Minimally Invasive Procedure". I thought, well, I can perform an acoustic procedure on him in response as a thank you for the surgical procedure that he performed on me. I haven't heard back from him yet, but you never know, he may have actually listened to it.

### **00.39.29 KERRI CARGILL:**

So Andrew, when I heard you on radio one morning, you were doing a guest spot talking about a lecture that you were going to do later that day on post-perfusion syndrome. And I was so excited to hear somebody actually publicly

talking about it, and I said, I've got to go to this lecture today. I turned everything upside down so that we could go and my mum came with me and you stood up and gave a 20 minute presentation on post-perfusion syndrome. And I cried and cried the whole way through: it just touched such a raw spot within me to hear you standing up talking about it, saying that it was real and so many of the things that you described were valid for me as well.

**(Andrew gives lecture)** A friend Googled, and what she typed in was “emotional after-effects of open-heart surgery”. And it was like Pandora's box opening. If you Google on that, you'll find a wealth of academic literature about the emotional after-effects of open-heart surgery. It's well known, it's well documented, it's thoroughly analysed, there are statistics galore, but none of that passes through to the front line delivery of health care.

**(Kerri Cargill continues)** I was looking for some sort of, I guess, support and information from that. And then I had to pull myself together to go up and meet you.

I have left work for the time being, and that has left me to create a whole new life for myself. And that has been a little bit of a challenge, I must say, because work provides a lot of structure. It provides a lot of social interaction and opportunities. And it also was for me a very big part of my self-identity and self-esteem. So to have to move away from that and create something totally different is quite a big process.

**(Kerri Cargill gives lecture)** Thank you so much for welcoming me here today. It's quite a privilege for me to come and speak to you all.

**(Kerri Cargill continues in interview)** I volunteered to lecture to the ANU Medical School. I lecture to all the new interns, nurses, and allied health professionals about the patient experience. And that is what I find immensely rewarding.

**(Kerri Cargill's lecture continues)** At the six month mark, I returned to work. However, I had difficulty concentrating, grew increasingly anxious, frantic, confused, and I was in tears at work every single day. I questioned why couldn't I perform at the level and intensity I used to? I was so very, very lost. A friend recognised I was struggling and took me to the GP, and so began my journey in our mental health system.

### **00.43.13 ANDREW - NARRATION:**

One of the most helpful ways that patients can meet each other is through social media. Various pumphead groups are active on Facebook, including Peter Gallagher's own support group for Australians and New Zealanders.

**(Andrew)** So this is Peter Gallagher's pumphead site, and I've just found a little post he put up. "I've had five open heart surgeries and so have my friends and family." It's very important we remember that, that it's not just

about us, it's about our friends and family too. And he says "I'm grateful for their love." And it's so important that we say that because we forget to say thank you.

**(Andrew's narration continues)** It was on a very well run American Facebook group that I first noticed some self-analysis being contributed by a Dutch psychologist. She had had open-heart surgery herself and spoke very eloquently from first-hand experience.

#### **00.44.18 LISETTE BREUKINK:**

You can see the Hague from here, and the university part of the city and Rotterdam over there.

The physical recovery was pretty easy, but the PTSD which came from the surgery made it so that I started to be upset about nothing. If I start to run, I start to cry. I do too much machines in the gym, I start to cry. It still happens now and then. And then it's just the over-triggers of the body which I have to take care of still, but the body itself can do it easily: it's extremely strong. This valve, it will outlast me. That's not a problem at all.

You find out that the psychological, spiritual thing is not working and you cannot go back to the brainy, having a lot of meetings, working nine to five. Impossible to go back there because halfway, during too much complex talks, you get the brain fog, you get the traffic jam. You start to find words which are not there. But you need to find a life where this quality is not needed and where you have everything being very quick. And you need to change. Find new ways and that.

It is not depression. Depression is really a black hole where you cannot step out. And this is what's really different. The whole, I think this whole body, of course, it's under complete anaesthesia, but the body remembers it. The body is still in shock. The body starts to tremble, this stopping the heart, cutting it open, closing it again: this is such a shock for the body that gives the PTSD already, I think so, and you have to recognise that.

The PTSD is from the heart surgery. It's just like cutting my life in two. But after that, you get this pumphead syndrome and this is more the, how would I call this? You get a burnout from wanting to be the same person and you don't succeed and you don't understand why you don't succeed. And this is why I do this, help you with this film because people don't recognise this and they try and they try in the environment they expect from them, by now, they should be normal, and they don't succeed, and then you get this total burnout. And people think is a depression, but it's more burnout and a complete fatigue than a depression.

The invisibility, you don't see there is this pumphead. People cannot guess. In the first, you cannot guess it yourself. You don't know what's happening. Next step is that you learn how to deal with it. But then another step is to

inform your loved ones, your environment, what has changed, and this can only happen if you took the first two steps. You have to be your own manager of the process, because nobody will do that for you.

I think we are really alone on this road and I would even go further, sometimes lonely.

The group is set up, I think, 10 years ago, and it's organised by Delft City for taking care of the other citizens. They call it the social program and they have several groups like cancer groups, and this one especially for our kind of people.

This group is teaching me to accept more who I am, and that doesn't come from a therapist or whatever. It comes from seeing other people also struggling with it and finding solutions in their way or not finding solutions. Or sometimes we shed a lot of tears, like yeah, it's you see the reality, how it really is. It's unavoidable. Other patients who lived the life with the same problem, they found solutions which psychologist, psychiatrist, a neurologist, cardiologist cannot explain to you how to live in life. And that's extremely valuable, actually more valuable than I ever thought it would be. Yeah, because they come with a life experience.

Last time I had problems with my boyfriend, how to adjust, it went kind of difficult, and one of the guys, I think 70, yeah, he told me, "But you have to take in consideration the position of your friend too. Maybe he is just very sad or he was upset. He doesn't know how to deal with it. Start forgiving him. Start to be just happier. Don't start expecting more from him than there actually is." That made so much light in me. The psychologist in a hospital will not be able to tell that so clear as he did to me, and this kind of people I meet in that group, and it learned me a lot. It's so instructive and the lady who organises it makes it like the best coffee corner in the city, and we eat cakes and we make jokes and we sing together because that's good for the brain. We make a lot of jokes actually with each other. So they will joke about you too. When things start to be too difficult, it's easier to make jokes about it. They start with making jokes right when you get in. It's actually very loving the way how they are with each other.

#### **00.53.30 ANDREW - NARRATION:**

I gradually became aware of a pattern that seemed to be emerging among the patients in this film. All of them appeared to be very proactive about engaging with the world in ways that were very different from their lives before surgery. They all seem to be taking strong steps towards building a new life for themselves, despite their ongoing challenges. I commented on this to Dr. Murphy and she had a very interesting response.

#### **00.54.13 DR BARBARA MURPHY:**

I think what you're seeing there, Andrew, is what we would call post-traumatic growth, and we see this in a lot of people after they've had a traumatic

experience, which a heart event is. So they've really had an existential crisis, and following that in terms of starting to make sense of what's happened for them and starting to regain a new sense of self, there is for some this period of post-traumatic growth where it might incorporate parts of their old self, but it's also like taking on a new version of themselves or reinventing themselves. And it can take many, many forms. It's so different for different people. And it's not like people have gotten over their trauma, or the trauma's finished. It's almost like the trauma informs their new self, and so the trauma is still part of them, but they have a new meaning and a new purpose in life. We often do see that.

#### **00.55.12 PETER GALLAGHER AND GRAEME SUTTON:**

**(Graeme)** I sort of feel the medical system let me down, but I've slowly come to terms with the fact that that's just how it is sometimes.

**(Peter)** Because they didn't diagnose you?

**(Andrew - narration)** I went along with Peter Gallagher one day when he went to meet another pumphead advocate, Graeme Sutton, and I was impressed by their determination to make a difference in the world.

**(Peter)** I think we're really lucky though. Like we're at this stage, I guess as a society, that we're ready to discuss these things. And I think too, we're probably a little different because again, so many of us who survived heart surgery, 20 years ago wouldn't have.

**(Graeme)** I wouldn't be here 20 years ago.

**(Peter)** Now we're at this stage where we can talk about pumphead, we can talk about the experiences, and we can talk about our need for assistance, and I think that we're kind of at that tipping point where rather than being pissed off that we haven't had the discussion, we need to be able to go, well, let's be leaders and ...

**(Graeme)** And set it up and help other people.

**(Peter)** Yeah.

#### **00.56.07 PETER GALLAGHER:**

**(Peter - interview)** I'm happy to go out and speak to medical people about my experience and to help others. My big focus is that they need to start talking about things beyond the physical.

**(Peter's lecture)** I've got this moniker of "That Heart Guy". And there is a good reason for that. We're going to work through that probably over the next hour, hour and a half. I'm not clinically trained the way you guys are, the way Steve is, the way the people that have treated me are. So I tell the story the

way I tell my story. So if I use terms that you kind of go, "Oh, it doesn't sound exactly right", maybe it's not, but I think it's pretty close most of the time.

**(Peter - interview)** I want to start helping engage that conversation around the fact that getting well isn't just being able to lift heavy things. So it's also making sure that you're well mentally, emotionally. And sometimes if somebody is not doing the lifting heavy things, maybe it's because there is something else going on and that needs to be addressed as well.

Maybe it shouldn't just be a letter in the mail that says you've got eight appointments booked in over the next three months to turn up to X place at X time and do cardiac rehab. But you know, maybe there should be more of a conversation around "we want you to come here because we're going to go on the journey with you".

#### **00.57.34 JESSICA CAUDWELL:**

I've relied quite heavily on my writing and my blog, blogging about my experiences and sharing them. And I've had people say to me that it's quite remarkable to be sharing such a personal story with perfect strangers. But I just feel like if I've struggled with this so much and finding someone to talk to, then I'm guessing that everybody else has the same problems as well. Let's get through it together and we can talk to each other and if some good can come out of this whole experience, then that's all you can want. And so I think that has been a really good anchor point for me to get through whatever I'm feeling.

The Heart Foundation has their Jump Rope for Heart that they run as well, which I've actually volunteered with. And so we go out to schools and we get kids engaged in learning about heart health and what's a healthy heart and I've become a real advocate for getting that awareness out there.

The pumphead is definitely still there. It's definitely still in the back of my mind, and I'm not going to sit here and say that I found this magic cure to magically, you know, "I've got rid of it and I'm all better now," because I'm not. As much as I still suffer from the anxiety and the sick feeling in my stomach, I'm better and I'm stronger for it. And just express that, "No, this is what I need and I'm not going to settle for less than that."

#### **00.59.31 KERRI CARGILL:**

It turns out I love travelling. I have had quite a few travel adventures. In two weeks time, I'm off to Europe and post-perfusion syndrome doesn't impact me when, oh, actually that's not true. Sorry, I'll stop there. I was going to say it doesn't impact me, but it does, because I forget where I put things. I went to New York in June, which was extremely exciting. I saw five Broadway shows and I've got all the energy in the world now to do anything I want to do. I went to see Bette Midler in "Hello, Dolly!" on Broadway. Once I realised I could

travel and go and see her, it was the most exciting thing. And we had front row seats and that was the most amazing, exciting moment. And when she came on stage, everybody just screamed and roared and clapped. And I think I was the loudest. I was just her hugest fan. We loved every moment of that show. It was just beyond my wildest dreams. It was fabulous, fabulous fun.

I love travelling because I feel very free, like a free spirit that can go anywhere and do anything because I'm so fit and healthy now. I feel like I just want to spread my wings and fly and that sense of freedom and the health that goes with that, it's exhilarating.

#### **01.01.05 ANDREW - NARRATION:**

With Kerri, what the psychologists call post-traumatic growth is clear in her sheer joy of living, and she later went on to be active as a volunteer in the mental health domain.

Peter Lynskey was also a committed volunteer, for him, in sports medicine. He worked with disability groups and volunteered with the 2000 Olympics and then the Commonwealth Games, a far cry from his earlier business career. He also worked for many years with seniors' indoor cricket, and when I met him, he was attending the finals in Canberra in the role of remedial masseur in the Queensland support squad.

#### **01.01.55 PETER LYNSKEY:**

The team that I chose was the Over-40s team. They won the national title, and I was considered part of the team, so I got a medal as well, even though I didn't bowl a ball. I had a significant number of people that were injured during the week that I worked to help them recover to go back on the field and actually play in the final. To me, that's really satisfying.

I have a lot of anxiety. I do things that people deem that, oh, you know, Peter could do this, Peter can do that, but I'm really anxious about it. And I go in, I'm extremely nervous talking in front of a large group. In the beginning, I sat at the back of the room all week. I didn't want to be in front of the group. It's changed me that way. I might be having results and achieving things in certain areas of work and sport, but I'm really anxious about it because I'm thinking, well, if I get too excited and I have a glitch in the heart and the like, and I've got to deal with that all the time.

My wife being my primary carer, she's constantly aware of my needs. The fact that, as she's indicated to me, that when I had the heart surgery that she said it had a huge impact on her. I was searching for reassurance in that first 12 months and here we are, 2017, she's still providing that reassurance, which to me is critically important.

#### **01.03.23 DR ALLEN COOP:**

The procedure has forced a space into my life and I'm compelled to fill that space. And so the stress that I'm going through at the moment is determining precisely how it is that I am going to at least start filling that space because I don't want to sit in my apartment, staring at the wall for the next 30 years.

I've always been enormously active and it's a matter of determining what this next set of activities are going to be, given the fact that I've just had this huge sort of gulf, this huge canyon open up in front of me.

I just love playing the bass guitar. Playing music is just a joyful activity. If other people can get enjoyment from it, that just magnifies the whole thing infinitely. Music is much more about other people because I'm sure that the other people I play music with have equally deeply personal responses to what they are doing. So that's an enormously powerful sort of collective rite that makes it enormously therapeutic.

Society just isn't in any way prepared for the fact that people are going to be living for an extra 20 or 30 years, I think is the bottom line problem. And it's the baby boomers who are going to be the first group of people that confront this problem.

After having confronted my own mortality, I feel that I have far more to contribute in any situation, under any circumstances. And I'm compelled to do that, which is why I'm sitting here talking to you.

The experience of having the surgery and having the recovery, that's something that you can have absolutely no idea of whatsoever until you've gone through it because it's profoundly transformative. It's more than wanting to do something, it's a compulsion to do something, and it's just a question of whether society will actually let me do that.

### **01.06.35 LISETTE BREUKINK:**

I always wanted to make fashion. Now I just started to make fashion and doesn't matter how or when, just start to make them. That makes me feel that I'm part of the society again, to make something real.

I had to find new ways to feel productive again. The real change is that I needed to go from the talking, thinking, cognitive work things to creative, making, sewing, baking, art, because the first are extremely tiring, the second, like sewing, was extremely relaxing. I like to sew. Maybe if I had a big China oven to bake pottery, I would have made pottery, but I had a sewing machine, so I started to sew. I started to make for my friends a few hats and then everybody also wants such a hat. Very chic and in the same time relaxed.

What do I like to do? Make art, make fashion, make hats. No, not running a business for somebody else, not I.T. Now I'm happier than ever. That's, yeah, that's really true. And I wish everybody to find that out and that's why I'm talking with you so people can have an example of the letting go is not that, you don't need to be afraid of that.

### **01.08.37 ROSEMARY MANGIAMELE:**

I became very aware that it was very important for me as the carer that I had to look after myself too, so that I could always be there for Giorgio and be able to give, but also have to care for myself. And I guess that's where I've found my art was really invaluable.

Well, before, I was doing fairly conventional sort of paintings, choosing different subjects. Or if I'd go outside, I'd go down to Brighton or something. Beforehand. So painting the scenery in Brighton. So that sort of thing, just sort of for fun. Then slowly I started getting very confused. I think probably there's one, I titled it "Confusion." And this is just fiddling with the colours and wondering what was going to happen and really trying to work things out. So, and then when I looked at these paintings later, I sort of realised what some of them were. Like I think I call this one "Puddles of Tears" because there were lots of tears, trying to keep things together.

I really felt peaceful when I was sort of sitting and painting and trying not to let things get on top of me really.

Giorgio was my best ... he gave me most encouragement and sort of, in fact he said, why don't I give up work and paint full-time? So it was his encouragement that really kept me going rather than sort of giving up, saying this is hopeless. And it was that creativity that we connected on too because with his photography, with his films, he was very creative, and I think that's sort of really what we encouraged in each other.

The series here, the Contemporary Art Society asked me for an exhibition. I said, "I haven't got any painting." But then when I looked at this, put them together, I realised what they were about, and I called the exhibition "A Journey of Grief." And I was absolutely amazed at the interest that people took in it. In fact, I sold a number of paintings, which really surprised me. I thought, why would somebody want something like this? But they had connected with it apparently and sort of touched them. So that was a real surprise.

**(Rosemary reads from the Exhibition catalogue)** Whilst recognising the spiritual and psychological pain, she gradually found art was a wonderful resource to express the inexpressible and promote healing. The healing power of art evokes the essence of the pain in the depiction of her loss. Between the darkness and the dawning of a new life, Rosemary struggled to integrate her loss and explore aspects of what gives life meaning. These paintings are part of her journey to go deeper into her soul. She paints to express her thoughts and works with the images to express her feelings. The artist's journey now becomes the viewer's journey.

### **01.11.59 CONCLUSION: ANDREW AND LISETTE**

**[Andrew - narration]** So the conversations and the searching continue.

**(Lisette)** It's interesting, now we are talking and there's something jiggling under the surface, and I have a feeling we are just not getting there.

**[Andrew - narration]** With pumphead, it can feel like there's no rest, no safe place, no security. The syndrome changes constantly.

**(Lisette)** I thought I was in command, but I had the illusion I was in command. But as soon as it can let go, the ego and the command idea, you can let the universe come in and bring you much more creative solutions than you would ever think of yourself. And that is new.

**[Andrew - narration]** There's a heightened sensitivity like raw nerves, always there to cause trouble if we're not careful, but it can also unexpectedly trigger new priorities, new values, new creativity.

**(Lisette)** It's much better off without us wanting to be happy or us avoiding to be unhappy. It's much better to be at peace.

**[Andrew - narration]** Lisette is right. Peace, some form of peace, is what we're all searching for.

**(Lisette)** You're obliged with the new brain, with the pumphead, you're obliged to find that peace.

**(end)**