Appendix G

G.1 Paraphrase of interview with Stephen

Case summary:

Stephen was diagnosed with Ca Kidney in October 2000 at the age of 46. His right kidney was surgically removed a week later and he remained clear of cancer for eighteen months when tumours were found in his lungs. Stephen then had the first line treatment for his cancer, which was refractive to chemotherapy and radiation treatment, a course of intravenous IL2 (interleucin) aimed at boosting his immune system. Although this treatment kept the tumours stable it did not get rid of them. A range of possible new drug trials were investigated in London, and Stephen tried alternative therapies in Germany until April 2004, when it became apparent that the tumours were growing. In July 2004 further tumours were found near his liver and remaining kidney. At this time he became aware that no further treatment was possible and chose the palliative care route.

Stephen was the director of a manufacturing company and was married with three children: at the time of the interview his two daughters were aged 18 and 16, the older of whom was writing her Matriculation exams. His son was aged12. Stephen's wife has her own business.

He was interviewed at his home on 1 October and died there four weeks later on 28 October 2004.

Paraphrase of interview:

In response to an initial question about how he discovered he had cancer, Stephen described this as "dramatic": he passed blood and tests revealed a tumour "the size of my fist" on his right kidney that may have been growing for up to three years. He was "pissed off" as he had attended regular company medicals, including one three months previously, which had not detected anything. He emphasised that he had been telling his friends that blood tests and chest x-rays were not enough, they needed to have regular abdominal ultrasounds. He said he had felt occasional pain high in the back at gym, but "like many men [he] took pain casually".

His diagnosis was followed by the surgical removal of his right kidney, a radical right nephrectomy. Stephen followed this with an explanation of the chances of a recurrence of the cancer, which range between 5 and 35% depending on the size of the tumour. His tumour was large so there was a 35% chance that it would recur. He explained that there was no adjunctive treatment as kidney cancer is refractive to both chemotherapy and radiation; immunological work is the only option.

When asked what it was like to discover that he had cancer, Stephen described this as a shock: “one day you’re working out at the gym, the next you’re in hospital. I was 46 - it’s young! It was a big shock, a major blow.” In answer to a question about what came to mind when he thought about having cancer, Stephen said, “It’s serious. Let’s see how you fight it. You don’t give up in the first stage”. He then talked of doing a lot of research on the Internet and finding out about the disease, products, treatments and response rates. He explained that after the surgery he had remained “clear” until May 2002, in other words for “a good eighteen months”. “Then it showed up again in my lungs and all there was to do was the immunological work’: this was Interleucin (IL2) which he had in two cycles, with injections for six weeks and then two weeks off. “You’re trying to stimulate your own immune system to identify the cancer”. The tumours remained stable, in other words they neither shrank nor grew. When the oncologist told him that the chances of a remission were better with intravenous administration Stephen did this, describing it as “really bad, ten days in hospital at a time. You live your life by the second.” Although the response rate for the treatment is 5% Stephen said: “I thought 5% was worth trying. Once kidney cancer has spread it’s very aggressive”.

However, the tumours remained stable. “Then I had to decide about the next step”. Stephen then talked again of his Internet investigations and research into different trials and narrated a visit to a kidney cancer specialist in London and the treatment options discussed with him. These only had a couple of percentages in terms of response rate and “none of them seemed worth trying”. He chose to make visits to Germany for two weeks at a time and try alternative therapies recommended by friends. These therapies were “marginal even for the Germans” but they “kept me going, kept me stable until April this year”.

At this time Stephen had started coughing and the scans revealed more tumours in his lungs; these were growing. He was losing lung capacity from tumour growth and the affected lymph nodes near the lungs. By July there were additional tumours close to his liver and kidney and he thought: “how am I gong to handle this”. Although the specialist in London offered Stephen a place in a double-blind trial (he would not know whether he was getting the medication), he thought “none of that sounds hopeful so I’ll just take what comes and go the palliative route”.

When asked how his illness had impacted on him, Stephen replied “When you’re living with it, fighting it weekly, monthly, it does affect your personality. My wife said I was more sensitive and irritable. Subliminally, you know.” He noticed that: “[I] just sort of go down each week. There’s a steady deterioration in the condition”. He elaborated that he noticed his “capacity deteriorating”. He could walk less and less far before getting breathless, he is more nauseous, despite medication like cortisone there’s still weight loss, loss of appetite and fatigue. “So that’s where I am”.

When asked about how his family were coping, Stephen explained that they were all in counselling. He emphasised that his relationship with his son was very good and that they discussed all his son’s anger and frustrations, including the “why” questions, for example “why is this happening to me?” After the interviewer commented that they seemed to have talked about the cancer in the family, Stephen said they had been “very open” and hadn’t “kept it closed” and had talked all the way. “We’ve been getting the fears correctly talked about”. He wanted to “prepare them well in advance, although there were some things that you can only deal with when it happens”. Asked to clarify “this” or “it”, Stephen explained: “it is death; it’s very much there. We try to get it onto the table. (pause) I think we have done so, so far.” He described spending one-on-one time with his children so that they could tell him their thoughts, feelings and regrets.

Stephen answered a question about support by saying that they had received a lot of support, especially from his colleagues. He explained his job function, but was clear that stopping work in July did not worry him: “I’ve never defined myself by my job. I enjoyed the job and the challenges of it, but I didn’t identify myself with it.” He referred to Samuel Johnson’s quote that when a man is

going to hang in two weeks it focuses the mind wonderfully, and expanded on this by saying he was focussing on “making sure that the legacy I left was one of love for the family. Nothing else matters really. Financial things are taken care of …”

He then talked of having been brought up as a Jehovah’s Witness and “faith played a major influence in my life”. “It helps tremendously.” “I focus on this not being an end but an interruption. That there will be an opportunity to see them once more under better conditions.” Stephen went on to say “death is not a final black hole” and explained that planning and thinking of the future is part of us as human beings: “God places time indefinite in our hearts”. Referring to the chapter in Ecclesiastes that explains there is a time for everything and a season for every activity under heaven, Stephen emphasised that death is an end to that view of time. “That’s why death is so different, it’s an end to the definite/indefinite”. He enlarged on his belief in the resurrection, just as Jesus resurrected Lazarus, saying, “death is like a deep sleep or a rest to await the resurrection call”. He quoted “You’ll be with me in paradise” and said “that sustains me and takes away the sting. Sadness we still have to deal with, but the sting we can deal with.”

The interviewer reiterated that his faith really sustained him, but when asked if there was still anything he worried about or feared, Stephen responded that “‘it’s not so much death but what I have to go through to get there that worries me”. He explained that he had very little pain although he was uncomfortable and that he wanted to die “nicely sedated so there is no pain at this time, and no suffering and just drift off. I want to stay here, at home, and I want it to be quiet, not to leave any ragged ends.” He only wanted his family around if it was quiet as “no one wants to see suffering”.

When asked about his funeral, Stephen said this had been planned with his friends. He wanted to be cremated with a simple ceremony, just family, then a separate memorial service. He received a lot of support from this friend and his brother; they had talked in depth. He also gets support from his own brother and his mother; soon she would be coming up to provide “constant care” with him during the day; if he needed a night nurse, he would get one.

Stephen noted that the oncologist had told him at the end of July that he had three months, “so I’ve got October”. His GP thought “it would be shorter, but I think I’m going to surprise him”. “The main thing is quality of life”. Stephen explained that in the morning he had energy and he saw friends, in the afternoon he sleeps and then he’s rested in the evening to be with his family.

In response to being asked how he felt to be dying at 49, Stephen said “‘I’m sad that it happens to me when I’m so young. But on the other hand look at men who went into WW1 and 2, the terrible slaughters that have happened on this earth.” Stephen did not blame himself for getting cancer and believed it was chance, which he described as “like driving along and being hit by the proverbial taxi” but he reiterated his point that it should have been picked up earlier: “the medicals were inadequate”. “My getting cancer is not a mystery. Firstly I think it’s just chance. Bodies and symptoms are not perfect and something will go wrong. But I also think that how you handle emotional circumstances affects your well-being.”

When asked if there was anything this experience had caused him to change, Stephen replied that he had thought about a lot of issues. His father had been a provider who had taught him to focus on bringing in the bacon and raising children with values that would protect them and enable then to cope in the world. He’d realised that life was much more than “making money and then disposing of that money”, He had also become aware of “the kindness that exists in people and that’s humbled me. I would like to bring more of those qualities into our lives.” He did not look back over his life and condemn himself but felt life was about “the learning and the enrichment. Some of us bash our heads, others know it without that; neither is right.” In addition he was very active in the church and able to give service “in a more meaningful way” because of the experience of having cancer.

Stephen said his regrets were twofold: the first was things he could have done better with more insight, or not implemented in the way he had, but he balanced this by saying that hindsight was always 50/50 and “I’ve learned this now”; the second is that there is now a great stress on his wife with all the responsibility on her shoulders. He’d found people’s comments unhelpful at times, for example: “you’ll do all right, you’re a good person” and said that he found it silly to think like that as it had nothing to do with whether you were good or not.

Another comment he found “damaging” was: “God wants another angel in heaven”.

Stephen summarised his feelings by saying: “I am very sad that I’m dying but I don’t feel sorry for myself”.

The interview concluded with grateful thanks to Stephen and appreciation for his time when both time and energy were in short supply. When asked if he had any questions for the interviewer, Stephen asked about her interest in death and dying area and some discussion of the M.A. in Clinical Psychology research requirements and the interviewer’s interest in this specific topic as a result of her personal experience with cancer, ensued.

G.2 Paraphrase of interview with Gavin

Case summary:

At the end of July 2004 Gavin (47) was diagnosed with cancer of both lungs and the media stinum (the space between the lungs); the disease was already advanced and he was given six months to live. He had two courses of chemotherapy, which were not completed as the cancer did not respond and he reacted with bad side effects.

Gavin ran his own business together with his wife. This was a second marriage for both of them and he had a son from his first marriage and a stepson from his second; the boys were aged ten and twelve.

He was interviewed at home on 22 November 2004; he was reclining on a bed breathing oxygen. Towards the end of the interview Gavin's wife Angela returned home and participated. Gavin was admitted to the Hospice In-patient Unit (IPU) on 4 February 2005 and died there a week later.

Paraphrase of interview:

Gavin described in detail how he discovered he had cancer. He was feeling unwell: "I knew there was something wrong with me, but I didn't know what it was". He described this as feeling drained and sore, with a bad dry cough for most of April 2004. In May he went to his son's GP who diagnosed pneumonia and prescribed a course of antibiotics, which did not help. He was admitted to hospital for further treatment for what was still believed to be pneumonia and felt better for a while, but two weeks later "felt rotten". Early in July he returned to the doctor and said "look, you know it can't be flu because I've still got it, I still feel rotten" and he was sent for a scan.

He recalled the physician giving him the results in the following way: "I hardly heard him, my wife was sitting next to me and he said you've got cancer. And he was a very shy man; he didn't sit and explain everything. I never heard the word cancer. And all I, I looked at my wife and she was in tears and I thought you know, what was that about, and she said he just told you you had cancer".

Gavin then ran down the passage after the physician to get him to explain. He was told he had cancer in both lungs and the media sternum: “it’s abnormal for your age” and “it’s, you know, it’s advanced and it’s not good”. A surgeon did a biopsy and the opinion that “it is cancer and it’s not a good one” was confirmed. Gavin described this as “he gave us the truth of it” and then referred Gavin to an oncologist who was reputed to have “a better bedside manner” than others. The oncologist said. “You’ve got a big problem, it’s not something that normally goes away, you know, it’s not known to be curable”. Without chemotherapy the oncologist would be surprised if he was still here in January so he went straight onto the recommended treatment. He summarised: “To go from never being sick to two months later you’ve only got six months to go wasn’t much fun”.

Some exploratory questions about the cancer followed, and Gavin explained that he had four big tumours: one almost on his voice box that goes down on either side of his heart, a big one behind his stomach, one across his right lung, and “the original culprit”, one down his sternum in the middle. His symptoms were from the tumour in his right lung that had collapsed; this had not been picked up as Gavin still had 130% lung capacity and “out-blew the average human being”.

Prior to this Gavin described himself as “physically strong and never ill” although he had always carried too much weight: “I hadn’t been sick for a hundred years”. He said “he didn’t do pills” or even vitamins and “had an issue about going to doctors”. He went on to describe his experience of chemotherapy, which he described as “a dreadful thing”, “just raw poison and it’s hoping to kill”. He commented on how individual the reaction to chemotherapy can be, as he had sat next to people who managed relatively well on very similar regimens, but his system did not like it. For three or four days after one type of chemotherapy, it felt “like somebody’s pouring boiling water down your veins”. He went on to say “and it’s very ugly. I sat in the bath when I came home and it looked like all the veins that came from the one they gave me the drip in that were connected, all lit up, like there were lights in it, and it was on fire, it was just too painful.” The second type of chemotherapy he was given burnt when it went in, but not after that, although he felt very weak, sweaty, vomited a lot and “the constipation, the headaches, I had everything”. He felt very sorry for himself; however, he said “there’s nothing else, what can

you do?" "There's no sort of instant cure, you know, where they can get it out and throw it away."

Gavin did not complete the second course of chemotherapy as he decided to see which of his symptoms were the result of the cancer and which were the chemotherapy: "… was I feeling nauseous because of the chemo or was this the cancer?" He concluded that he did not want the additional suffering of the chemotherapy treatment: "In my opinion, look, to be flat on your back and feeling dreadful the whole day, not sleeping, not eating, I can't see the point, I'd rather take lots of painkillers (…unclear…) rather than go through that because that wasn't living that's for sure." He had felt so awful that "you know, if there was a switch I could have switched of, if I could have reached it, it would have been off, because I didn't want that. It really wasn't worth it."

However, Gavin said chemotherapy did work for some people and he cited his mother having had both colon cancer and breast cancer and having had chemotherapy after surgery "to clean out the last bits and hopefully kill any bugs in the blood". He had initially thought his cancer must have come from his mother but apparently it was not hereditary. When asked if he had any sense of how or why this had happened to him, Gavin laughed: "no, no, we joke about all one's sins and what you've done wrong, it can't be that. I mean I know people that are much worse than me and are fit and healthy, so it can't be that."

It was still hard for him to grasp that he had cancer: "It's a very big thing to get your head around, you know, four or five months, whatever it is, five months down the line and it's still a very difficult thing to swallow." Gavin thought that in the 22 years he had been in South Africa he had only had two days of sick leave: "I just was never sick, I'm not used to being sick, so it was a big shock for me to go from well, what they thought was pneumonia, to dying now, and you won't last long. It was a very hard thing." This change had been "instant".

Gavin expanded on how the oncologist had told him that he was terminally ill, saying the oncologist "didn't mince her words. I mean really, you're just not going to live; this is something that is going to kill you. (The oncologist) did that very nicely, by the way, but still." After the oncologist had explained what sort of cancer it was, Gavin said he and his wife had asked: "I think in everybody's nature is to find out well okay, well how bad is bad?" When he heard the

prognosis, which he referred to as “the nitty gritty”, that without treatment he had six months “I’d heard enough now, and obviously I just wanted to go home.”

He went on to say that at first he had thought a lot about how he was going to die: “are you going to be, going to be not able to breath or, you know, just suffocate, or have a heart attack.” He felt knowing was much worse than being killed suddenly. “I’d much rather have driven into a bus by mistake, you know, had a heart attack out of the blue, that’s a fact. I mean knowing you’re going to die is not a very, it’s very poofie, it’s not nice’”. He found the anticipation difficult: “as soon as somebody says six months, you’ve got a mental diary and you cross a week and a month off and you say two months to go, you know.”

Gavin said that on some days he felt fine “I don’t feel ill and sick and dying you know. It’s those days that I sort of give myself a whole stack of hope and say well, look, maybe my system’s giving this a clout, you know? Maybe I’m stronger than this. And of course cancer’s not a forgiving thing and it lets you off for a while but then it reminds you that you’re ill … it comes back, one of the feelings or the pain, … It’s very draining.” He spoke of how weak he now was, saying that it would take him ten minutes to walk to the toilet and back and that climbing the stairs was like “a marathon”. He is on oxygen and explained that he has tightness in his chest and tends to get short of breath when he exercises or gets emotional, for example when he thinks about his business.

When he was asked about his business, Gavin spoke again about his illness and said that although he was deteriorating, it did not seem to be as fast as anyone predicted, and that given the extent of his tumours, doctors were surprised at how well he was. People with tumours in just one lung had died sooner. He said: “the whole cancer thing is a big dark hole. I don’t really think anybody really knows too much about it, you know.”

The oncologist had repeated to him that they would just work day to day and not say, “well you’re going to choke to death” because nobody knew, and even if this did happen, there were painkillers and sedation and he did not need to be too uncomfortable or suffer too much pain. Gavin was already taking morphine as well as other painkillers and if he does not take them, he regrets it. He described the pain as “a crappy pain in that is a deep sort of aching throbbing

and occasionally even I get sort of long stabbing-like pains". This was the result of the tumour that was between his stomach and his backbone with all its nerves. He found the pain "bearable but ugly". He had lost 28kg in four months and was not sure that his "insides" were where they should be. He believed that he had survived as long as he had because he had muscle and "reserve for this thing to eat off" and if he had been "a thin wafer of meat" he would be in trouble "because what would it have lived on? It would have had nothing but to kill me, you know."

After talking about his difficulty in finding a comfortable position to lie in, Gavin said: "We take it all for granted. I can tell healthy people now we take a lot for granted. I was always the one who physically was the strong one." He spoke of missing his energy and being able to do whatever he wanted when he wanted to; "now I do nothing that I really want to do when I want it". The disease had taken away all the things that were important to him. "It changes the way you, just everything, the way you think."

He believed his life had been privileged as he had started a successful business, had made money and had travelled; he spoke of having had many experiences and feeling no need to go and see the Eiffel Tower, saying "I've had good living". "The things I miss are really the ability to live, to be able to run up the stairs and (pause) know that my child is going to have a father … the fact that I'm leaving my wife and my mother who's 78 is going to watch me go before she goes … it's backwards you know and I think, I suppose you miss normality, you miss what you took for granted - the fact that you live and you're healthy." He realised that the everyday inconveniences of life that people complain about are small and insignificant if you are told you are going to die.

When he talked about his family, Gavin explained, "the saddest thing of all of this is the inconvenience and the feelings and the trouble that the family and those close to you go through, all the emotions and things that they go through. My immediate thought after being told was that I want to be with my family, that there was really nothing else that I wanted." He concluded. "the family is the *horror"* and felt that in his situation support is all you have; everything else (money, possessions, business) is not that important. However, he was concerned about getting his affairs in order: sorting out his shares in the business and signing over the house to his wife; but he emphasised that family,

and being close to them was equally important. “I wanted, if I could be selfish enough, if I didn’t need the money, I’d ask my wife to sit here all day with me … having family close by is really the ultimate. It’s the only thing I look forward to.”

Gavin spoke about his family, his parents and sister, his “incredible” wife and his son, aged ten. He did not think his son fully understood what was happening, but saw him as important. “The hardest thing for me is knowing that they are sad over me. To be sad over something is fine, but not over me.” He thought what the family were going through, which he described as “breaking up”, was ”devastating” and harder than his experience. “Often now I believe it would be nice to just end it, so they suffer no more. The fact that they come and I’ve lost maybe a bit more weight, or I’m feeling really awful at the time, it saddens me that they witness it”. Gavin reiterated that his family’s experience was the worst part of his dying. He admitted that: “It’s not the physical act of dying that I’m scared of, I’m scared of death, I’m scared of the thought of dying and everybody else knowing it.” At this point Gavin was visibly upset and had a cigarette. He continued to speak of the support he had received from friends and of his closeness to his mother who sat with him over his worst periods but became more distressed.

The interviewer changed the subject and asked whether he saw himself as a spiritual or a religious person. He said not and explained: “I’ve had great problems with religion as a whole. I’m one of those very practical sort of people, that believe if I can’t touch it and see it then it’s either not there or it’s different to what everyone else believes.” He thought religion was probably a comfort for those who could believe but added that he had no respect for religion as a result of the wars fought in its name and the wealth of the Catholic Church that was not used to fight poverty. He added that when he felt depressed and felt sorry for himself and thought “why me, and you know why die and couldn’t it have been something I could have overcome”, he though “it would be nice if there was a God” then you can believe “there is something after life”. Again he said that if there was something, it was something “none of us could ever imagine, … something amazing, and maybe the soul of whatever in you lives on but nobody’s ever been able to show me”.

Gavin reiterated that his comfort came from the people around him and that their presence and the physical touch of his wife’s hand and the look in his

mother's eyes was "real warmth" for him and an emotional "injection of life", what he called "a far more realistic crutch". He saw his illness as "annoying and upsetting" and it made him "cross": "I'm just sick of being sick". However he had learnt through the drastic change in his life that "actually really all there is, is those close to you, that sort of love and the feeling the family gives you is really all it is. There's nothing more to it."

He reported that he loved things, possessions, making money and spending it: "I like achieving and I love money. I love the idea of making it and spending it. … I worry about it daily for my wife, who's now left here to fend all on her own." He believes that he *was* the business as "he dreamt it and lived it and made it and pushed it" and he found it hard to give someone else that responsibility. He saw that as stressful and a burden for his wife.

Gavin said that all his pain and suffering, although horrible, doesn't "equal five minutes of my Dad's pain … I'd have about fifty times if I could take my Dad's pain away". He believed that cancer is a "nasty thing, it's a disgusting disease" and expressed surprise that with all humanity's achievements, they still could not cure it. He thought about other ill people, people with Aids and others who are dying and wondered what the point of something like going to the moon was. "I mean why should a few lumps in your body kill you, with the way they transplant this and clone that, why should this be an issue? But I don't ponder over that much because it's life isn't it? They can't, everybody knows they can't, there's no cure … for all the cancers."

When he was asked if there was anything he would tell people in his position, Gavin emphasised the need to "get yourselves in order": "get your will, get your house in order, if you've got a company, make sure it's written in your will correctly". This was important so the family was traumatised as little as possible and to reduce your own stress when sick. He said he had been extremely anxious when he was first diagnosed and did not know how much time he had, and wanted to ensure that he did not leave his wife with the house as part of the estate and bank accounts frozen so she was unable to pay staff salaries or access cash. He noted that nobody expects to die suddenly and expressed regret at all the insurance policies he could have bought but did not. He had been reassured to find that most of his friends were "a lot better sorted out" than he was.

Gavin's wife Angela had entered the room and she commented that this concern was particularly relevant for men as they were used to being the head of the house and now "that rug's been ripped out". She believed that if he knew she was safe and would not have to worry, this concern would not play on his mind. She explained that after Gavin's diagnosis she had phoned all their friends and encouraged them to talk to him and ask him questions to make it easy for them. She noted that people felt uncomfortable when they used language like "I'm going to die if I don't get this" and suddenly realised that "now it has real meaning for someone else".

Gavin then commented that they also joke about his illness, not because it is funny but to make light of it so people don't feel uncomfortable. Angela felt that without this lightness the situation was very depressing: "He's not dead yet and up until that point we will celebrate the fact that he is still alive. And that means you still joke and you still play and you still have fun and you still laugh; because at the end of the day, he's still here. There's lots of time to mourn him afterwards." Gavin explained that one of his wife's great strengths was living and "not so much coping" with the situation "but being real about it". They both noted how scary the thought of death was for people: "they don't like it and they don't like to think about it; you can see they're all tense". This was why they had tried hard to "open the door" to real communication.

Angela admitted that there were some subjects that were very difficult to discuss, even for the two of them, like the funeral. But they had planned "a send-off he's going to want and something his friends can understand". Gavin then interjected and said: "not that I'm too fussed about that; as far as I'm concerned, it would be much better if they took me away and that was the end of it". She reminded him that the funeral was "for the people around you" and that "you've got to allow people to say goodbye'". They had agreed that there would be no viewing of the body as she thought that was "disgustingly awful", "traumatic" and that there would be children there. She concluded that they had tried to get the "really nasty subjects" out of the way quickly and "now we're just living, you know, and trying to make the best of it". Later she reiterated: "I think the biggest mistake people make is that they, the person's been given the death sentence and now he's dead, or they're dead, so let's just behave like it's a morgue around them".

Both of them then commented on people's awkward comments, like "get well" and joked about Angela's mother who is "this big heavy bible puncher" who was insisting that there would be a miracle despite there being no record of anyone surviving a cancer like this. They told the interviewer "she's a thesis on her own" and then joked about Gavin being "past his sell-by date".

Gavin noted that his feelings affected everyone: "you're a bit depressed and bad and that goes on for everyone around you, you know, because they feel bad and your family lives this thing with you. And Ja, if you're on a high then they're on a high with you big time". Angela agreed that it was wonderful when he was okay but that he did get depressed and for that she gave him "happy pills". She said she knew how fearful Gavin got when he wondered how he was going to die and whether it was going to hurt. She said he had not slept for a month after his diagnosis going round and round with all these "dreadful thoughts" and noted: "I try to, really do try to understand it, but how on earth do you, how do you think about that when you know you're not going to die tomorrow? So how do you put yourself in his shoes?"

Gavin believes that people are very adaptable: "it's just human traits built in, you become accustomed to something" and "you start to get used to the idea that this is going to happen. It doesn't mean you don't get sad and you don't get very self-absorbed and depressed. You do, you get all those things". He went on to say that he worried that his "good periods, short as they are, will just fizzle up and then I'll just feel poxy all the time". He hoped to still have a few good days among the rotten ones. Angela noted that Gavin did not have good days any more, and he explained "just good time slots". She encouraged him to take more painkillers saying: "He kept thinking he's going to get addicted, and my point is - excuse me! If that's your problem then that's the least of your worries, you can be high all the time as long as you're not in pain." Gavin said he did not enjoy the feeling of floating and being out of his body. The couple reiterated that it was a good thing Gavin had been so big and strong and that was why he had been able to keep going.

The interview ended with grateful thanks towards both Gavin and Angela for their willingness to talk openly. Gavin hoped it would help others find out more and be more prepared. Finally, the interviewer wished Angela a happy

birthday, as she knew that Gavin's friends had been shopping for a special dinner he wanted to make for her.

G.3 Paraphrase of interview with Sally

It is important to note that the audio quality of this interview was poor, possibly because Sally was the only patient interviewed who was in bed and it was hard to position the microphone and possibly because the amount of morphine she was taking made her speech somewhat slurred.

Case summary:

When Sally was diagnosed with Ca breast in 2000 at the age of thirty-three the cancer was already quite advanced as a result of what appeared to be a combination of neglect and medical mismanagement. When the adjacent lymph nodes were dissected, eight out of twelve nodes were malignant. At the time she was living on the south coast and she had surgery and her first chemotherapy treatments in KwaZulu/Natal. Later she came to Johannesburg and tests revealed the cancer had spread to her lungs and her bones. Although she had further chemotherapy it was ineffective. Palliative care was started and radiation treatment was used to reduce the pain in her bones. Sally was interviewed in the In-patient unit at Hospice where she had been admitted for pain management.

Sally was married to Larry and they had a six year-old son, Jack. She described herself as a child minder and had spent a number of years looking after street children; Larry works as a carpenter.

She was first interviewed together with her husband on Sunday 21 November 2004 but this was stopped when visitors arrived; interviewing resumed on Tuesday 23 November at which time she was on her own. Sally coughed frequently during both interviews and was uncomfortable and at times in pain. She died on 21 January 2005.

Paraphrase of interview:

Sally initially spoke of her pleasure at being interviewed when she had been thinking so much about her life. She emphasised that she believed Jesus would heal her: “Do I really believe He won’t heal me? No.” She spoke of previous hard times when Larry had been in England and she had been looking after children on her own without much money and how she was used to

“waiting on God and praying not knowing what to do”. She used to read and particular Scriptures and songs about being healed frequently came to mind.

Sally was aware had a “lump on my chest which I wasn’t too worried about”. She went to the doctor who said it was just “a milk gland or a blocked gland” and she explained: “I didn’t know about cancer, I didn’t know about having a biopsy”. When she phoned because she was worried the nursing sister said: “If he says it’s nothing then it’s nothing. Just leave it.” Sally explained: “I wasn’t worried about the lump until it grew bigger and bigger and eventually I couldn’t hang my curtains up it was so big.”

After about a year the lump was removed. The day Sally was due for her feedback appointment with the doctor she was ill and there was another month’s delay before she got the results saying the lump was malignant. Three days later she had a mastectomy of her left breast and almost immediately started chemotherapy. At this time she and Larry were living on the south coast and they needed to travel to Durban for chemotherapy. This was difficult as they were short of money and they’re car kept breaking down. In addition Sally was very sick and vomited a lot.

Larry complained that the most frustrating thing was that they did not really know what was going on: “They just don’t tell you. They tell you actual lies.” He believed that if they had been private, paying patients it would have been different. This had not improved once Sally was treated in Johannesburg as part of a big clinical trial. Larry explained that although they were grateful for the medication, he found the doctor in charge very rude: “his bedside manner and trying to get anything out of him, it’s like trying to squeeze water out of a stone”.

By this time the cancer had spread to Sally’s lungs and there were too many tumours for surgery. She found the new chemotherapy harder as Larry was away earning money and she was under pressure from her family to change her lifestyle. “They wanted, they saw a different life for me. I had my dogs, I had my child and they sort of wanted me to conform to something else. If I did then they would help me. And I couldn’t so I just had to stay quite strong.” Her faith had helped her through this time: “I just had this hope and this strength that God would heal me. And when the fear came you know I could deal with

it." At the hospital she met another woman with three children who had been battling cancer for nine years; she also believed in God but she died. "That was really hard for me to swallow".

When Larry returned it was found that the cancer had spread to Sally's bones and she had another six months of chemotherapy. She found this less hard than the first two lots of treatment. However, the cancer was not "everywhere, arms, neck, spine, everywhere, hips." Palliative radiation treatment had really helped reduce the pain of this. She was in the IPU to try and manage the pain and adjust her medication. She said: "my elbows are very sore today. But not all the time, this sort of shooting pain. You know, it shoots and takes me by surprise."

Larry then expressed his anger at the original doctor on the south coast saying, "it's actually his fault this has happened". He blamed him for not doing a biopsy when they had first consulted him. Apparently the doctor had said, "don't worry my girl you're too young". Although Larry had spoken to a lawyer about this, he had been told "don't even bother trying to sue the medical profession because you won't win". However Sally said: "Shame I don't blame him, I just feel he is a person, and the Lord is talking to me about healing so I know this is even his plan for me, I really believe that. I really really believe that."

Larry explained that he thought part of the problem had been that neither the doctor nor the nurse liked Sally: "quite a few people get irritated by Sally's nature, because she's very much of an individual person. She's got different values and sees things differently to them. And a lot of people get intimidated or offended by that." At the time Sally had been looking after street children and they tended to go with her to the hospital, which people didn't like. There had been a similar pattern with the nursing sisters in the Johannesburg hospital who had sometimes reduced Sally to tears by making her wait until last for treatment although she had been waiting since 7am. "On the one side, as a Christian here's this amazing encouragement from the Lord, and here's this other thing, that's completely negative."

Sally that said: "Now we've sort of got to a point where oh well there's nothing we can do for you." She reported the doctor saying, "we can give you some chemo, there's only a 10% it might work so basically it's a waste of money"

“because it won’t work”. Larry reported that things had been better since Sally had been at Hospice as they seemed to have found a balance between having no pain and being totally drowsy all the time. Now he was able to have a conversation with her.

Sally then spoke of her son: “I’ve thought about dying, actually thought about dying, you know to leave my 6 year-old son, is just too much, I can’t do that to him. I can’t even think about it.” When asked if he knew how ill she was, Sally said that Jack “knows that I’m sick and he thinks I can heal”.

When asked if she had any thoughts about why she had developed cancer Sally said she thought it was “emotional” and explained that the marriage had been volatile and difficult. At one time she thought she would have a nervous breakdown. However their relationship was better now and she “tried not to moan about it too much, not to be a burden”. However they had been living in a small space with her dogs and that had been a strain. Larry emphasised: “The thing is without faith I don’t think I’d survive. Faith is the hope of things you cannot see. That’s that hope that’s faith. “

After Larry had left, Sally spoke of how hard it had been to get the diagnosis: “When I got there, the news the first, first time all I wanted to do was jump into the car with my child and run away.” Although her breast had been removed she gestured to a lump on her chest that had since grown.

Before Sally was interviewed for a second time, she had seen a Hospice social worker who had encouraged her to make a plan for her son. She grieved: ”I’ve got to get my mind around this thing”, and “people do die, and I do get scared. And I should never never never be someone this happens to, I should never die… day by day I’ve thought about cancer. To be given a six year-old child to die on him, to me that just doesn’t make sense…” Leaving her son without a mother was the hardest part for her: “Well I wouldn’t mind dying, It’s quite a privilege for me, and I wouldn’t mind…. you know I wouldn’t mind, I believe in heaven I believe in Jesus”.

She felt that she had a plan for Jack and was pleased her father would take care of him: “bless my father, because he’s paying for school next year, and the school uniform, which is amazing, like he just stopped everything and said no,

(little laugh) Jack's not going to Emmarentia, he's staying at a Christian school. Which is what I wanted to do." She felt progress had been made as the family was "all a team now" and it was no longer just her and Jack. However she worried about whether her stepmother would be good to Jack.

Articulating each word very clearly for emphasis, Sally explained: "I don't want to go. Basically ... I don't know that if you really don't want to go, you don't go. I'm not sure." She talked of her faith: "It's all very well to say we're human, you know, but God really expects us to understand what trials we go through. To understand that when the later glory is compared with where we are at, you just can't compare!" However she felt very bleak and "I feel like I'm losing all hope now." She felt very sad and just wanted to cry and cry.

Not long after this Sally became more and more restless and uncomfortable and she called the nurse for more morphine. The interview ended and she was thanked for her input and told how much it was appreciated especially when she was so unwell. Sally said she had enjoyed talking and thinking things through.

G.4 Paraphrase of interview with James

Case summary:

In June 2004 James (52) was diagnosed with colon cancer. He had the malignant piece of his ascending colon surgically removed but chose not to have chemotherapy. Instead he used alternative therapies, which included a raw food diet, vitamin supplements and other homeopathic treatments. At the end of January 2005 cancer was discovered in the lymph glands around his lungs although his lungs were clear. He was told he had just months, or even weeks, left to live.

By profession James was a contractor in an information technology (IT) business. He had been divorced since the mid-1990's and had two children, a stepdaughter who is twenty-two and married with a baby, and a son aged sixteen.

On 16 February 2005 James was interviewed at the home of friends who were caring for him; he was on oxygen at the time. He died five days later on 21 February, the day after being admitted to the In-patient Unit (IPU) at Hospice.

Paraphrase of interview:

When James experienced severe stomach cramps in June 2004 he thought he had bad gastro-enteritis. He tried some medication but nothing helped. He had noticed a bit of blood in his stool and went to the doctor, commenting that he hated going to doctors, and was given antibiotics and the problem seemed to be clearing up. He spent the weekend and the Vaal Dam and woke at 4 o'clock in the morning on Monday with "the most incredible stomach cramps" and could not get up because of the pain. He said: "I realised I was in serious trouble". He phoned a neighbour and a friend took him to the doctor who sent him straight to hospital to see a surgeon. James had an emergency operation for a blockage in the bowel caused by a cancerous growth.

He was then told to go to the oncologist and said: "I wasn't terribly impressed with the guy, miserable fellow as far as I was concerned." So although he had a port fitted for the administration of chemotherapy, he chose to follow

alternative cancer treatments recommended by his brother and a herbalist friend of his. He had previously been what he called “a typical South African - meat-eating, beer-drinking, bread-eating”. He went on what he described as a “strict regime if you like of eating veggies and cutting out this and cutting out that and blah blah blah blah blah”. His health improved, he returned to work and went on holiday at the end of the year.

A month prior to the interview, at the end of January 2005, James developed what he thought was a chest infection. However this turned out to be cancer in the lymph glands all around the lungs. These were “chewing up” the lymph glands and blocking them; the glands were getting hardened so he was “starved of oxygen”. He concluded: “so the prognosis is that it’s weeks or months rather than years for them to deteriorate”.

James said his chest was “not painful, it’s discomforting, very discomforting”. He had only been on oxygen for a few days and he was due to start morphine that day; this apparently relaxes and helps to open up the air tubes. He explained that if he was not talking he was fine. The interviewer said he must tell her if he felt uncomfortable and would like a break.

When asked whether the rapidity of the illness had been a shock, James replied, “you could have knocked me over with a feather”. However he went on to say “although, in a way …” and explained that his father was about his age when he was hospitalised for a kidney stone operation and was found to be “riddled with cancer”. However, James did not know whether his father’s was colon cancer, and then said he thought “this colon thing was actually an offshoot of the main cancer” because he had no further pain or problems in that area at all. He continued to talk of the shock of the diagnosis saying “it was absolutely unbelievable” that in eight months his life had gone “upside down”.

He went on to say that “I have a philosophy that when it’s your time to go, it’s your time to go. There’s not a damn thing you can do about it. Some people last not even a day, other people last over one hundred years. Some people never abuse their bodies, they die young; other people abuse their bodies all the time and they die old.” When asked, James thought he was 50/50 on the abuse- or not-abuse-your-body spectrum. He was a smoker, “30 a day, 40 on a

bad day", but described himself as "never an over-the-top drinker" although he could "tie one on" at a party and drink "copious amounts of beer".

In answer to a question about what work he did, James said he was in the IT business, working as a contractor, and said this was stressful. He believed "a lot of what cancer is, is stress. Or it helps it on I should say." He explained that he had experienced a stressful divorce and retrenchments: "I went through a stage in my life where I always seemed to choose the wrong thing. You know how it gets sometimes when whatever you do turns to mud rather than gold." This had lasted from 1994 until about 2000 when he had got a 3-week contract and where he was still employed.

James believes that "all of us have some form of cancer in us; I think it's just some catalyst that triggers it". He expanded on this: "You know once you've got it, I don't care what they say, I mean the studies I've done on chemotherapy and that, you know they basically take you away for 6 months with chemo, drug to the whew! to the limit and send you home to die". When the interviewer checked with James her understanding that he did not regret his choice of treatment choice, he emphasised: "no, not at all. I've had a good six months, I really have."

The interviewer asked if James's approach to things had changed in the last six months. He replied that he had cut down on the beer so that although he still "felt like a dog" in the morning, it was not as bad as he used to; he had also varied his diet a lot more, although he called this "like closing the door after the horse has bolted". He expanded on the details of his diet, which had been all raw food, no animal protein or dairy and lots of vitamins and supplements. However, he believed he should have had a lot more oxygen therapy as "oxygen kills cancer".

James compared his health to his brother's, which was good, but admitted his brother had stopped smoking earlier than he had. James went on to say that he, James, had not had a live-in partner since his divorce in 1994 and he believed that had contributed to his less "balanced" way of living: eating fast food like pizza and burgers, and not having fruit in the house. He said "I think being a couple definitely modifies your whole eating pattern".

When he was asked about his children, James said that he had two children - a married daughter and a son aged sixteen. He felt this was “the worst part” of his situation. He explained that he was thirteen when his father died and “I know the things I missed out with me”. He had wanted to get his son educated and tour around with him, what he called “go and actually see the university of life”. This might include mingling with local people and seeing their traditions, as well as going into a pub and “listen to a brawl going on”. Although he clarified: “not that I was a big fighter ever, but you know, how to handle himself”. He also wanted to continue taking his son to the bush and sailing, both of which he loved.

James said he had a sailing boat and he and his son “‘had some good times, really good times already”. James had spent months renovating the boat and his son had helped; they had sailed it together two weeks previously. However, he was selling the boat: “I’m trying to get things sorted so it’s all sorted. You know it’s not like I’m going to go tomorrow, so I’ve got a few days, or a few weeks whatever to get my house in order. Going through my wills and documents and tax papers and insurance policies just to make sure that it’s all that. (he gestures) So there’s a box. That’s it, tie it up.” He noted that he was an accountant by training so “now everything must be in its place” but said “it’s hard!” He recalled the time of his mother’s death nearly four years ago (which he called “passing away”) and how easy sorting things out had been as she had been very organised. “I’m trying to make sure I’m in the same sort of boat.”

At this point the interviewer suggested a break, which she called “a breather” as James was coughing frequently, his breathing seemed laboured and his talking slow.

After a ten-minute break James explained that he got a build-up of phlegm that made him cough and he thought this was from his smoking days. The interviewer commented that he seemed to have done a great deal of reading and James said he had downloaded about five hundred articles from the Internet about drug trials and for and against chemotherapy.

The interviewer asked James to expand on his experience with the oncologist. James said “I thought he was a prick” and when asked why, he rubbed his hands together saying “money, money, money … that’s really what it’s about.

There's no compassion there." He explained that the oncologist's secretary had phoned him and quoted the cost of his treatment and his first payment. He spoke other people who had been to the same oncologist and found him "heartless". He thought surgeons did great jobs saying "you know they fix and repair things" but he was less confident about other doctors. He believed the American FDA "pulls the wool over people's eyes" because a natural product cannot be patented.

He suggested that perhaps he was "not strong enough" with his treatment explaining that he might not have strict enough, and that there were some products that were not available in South Africa. He said "I'm sure many people have been cured" but he had been "going downhill" since the middle of January when he had developed a sore chest. A friend of his had also had one and they concluded it was a virus. After going to his GP and getting antibiotics, cortisone and a pump, he still felt ill and was sent for x-rays. At this point James exclaimed "whew!" All the GP said was to go to the oncologist: "he knew, but he wasn't telling me". James had no explanation for what this might be about and he went on to say that the Hospice doctor was "the first person that actually explained to me what those x-rays meant". He continued: "it was a relief to know how exactly – 'cause I said to her I want it straight up, not beating around the bush." This doctor had drawn pictures "which made it easy to understand my pain". (James had been referred to Hospice by the friends he was currently staying with.)

James emphasised: "I would rather know where I'm going. I don't want to be put on lung machines and all sorts of things. I'm happy to accept this bit of oxygen, but I certainly don't want to be pumped full of goodies and gafters and things to prolong my life – for what? You know, where's the quality of life?" He wants to "just go out gradually you know, gracefully should I say. Rather than this adrenaline in here and pump this up and get the heart going and then the kidneys. Just quick". He continued: "What I would hope for it just to be able to close my eyes and that's it. Go for the big sleep and that's it. Reality says that's not going to happen."

When he was asked whether he imagined other people would be there, James replied: "I'd prefer people not to be there at the end. Rather just remember be the way I was. You know that they get a phone call to say I'm gone. But they

mustn't open me up and display me in a coffin and all that. I want to be cremated and take my ashes to the Vaal Dam. Have a bit of a party and scatter them in the water." (He blows his nose.)

He then talked of the fun he had experienced at the dam in the last three or four years: "I mean I'd get to Friday morning and I couldn't wait to get to the dam". He explained that he had a park home at one of the yacht clubs and he "played" with his boat. He called the time on the water "therapy" and a time when he did not think about work at all. In order to have a long weekend at the dam he used to take his son to school at 6.30am all week and go to work, and then fetch his son at 1 o'clock on a Friday and "the two of us would just disappear and just use a whole afternoon extra".

James reminisced about the time he had spent doing things with his father (like painting the wall or whatever else was being done) and that he had done the same thing with his children and it had "paid dividends". He also liked the fact that at the dam, teenagers "get filthy dirty in the mud" and "have an absolute ball" and there are no shopping malls.

The interviewer then asked James about his daughter. He explained that she was his stepdaughter, twenty-two and married with a son of just over a year old. After the divorce James had the children with him every weekend, but after a disagreement with his ex-wife this had changed and the relationship with his daughter had deteriorated. However, they had reconciled and he had organised her wedding, referring to their relationship as "nicely knitted at the moment". He felt his illness had been a huge shock for both children. He had only been off work for two weeks when he had his operation the previous year and "I started going up and up. And only January it suddenly phip!"

James wondered if his family's high pain threshold had made a difference and recalled that when his son was a baby his ears would burst before he cried from the infection. He said that he had been physically fit from working on the boat, which had been hard manual labour. The change between how healthy he used to be and how he was now was very frustrating for him and made him want to "pull my hair out". "I can't do things. I can't walk from here to there without huffing and puffing'. He admitted he was feeling hopeless. Then

reiterated his philosophy and said “if this means living short, you got to accept the facts and go from there and make the adjustments”.

When he was asked what he found supportive he answered all the phone calls he received and the things people did for him, for example someone, and he did not know whom, had organised and paid for the oxygen. The friends he was staying with were “fantastic” even though he had “turned their life upside down”. James then spoke of how early he work and of being an early riser, saying “I always found that the best part of the day, so I open the curtains, just breathe in the fresh air.”

The interviewer asked if he was a religious person and he emphatically replied “not at all. Don’t want any religious stuff near me. Nothing. Very specific about that.” He believes that religion is just “self-centred bigots after their own interests”. Further questioning about his beliefs elicited the following explanation: “We are organisms. We’re not something that’s made up spiritually, … we’re an organism, and the ant, whatever, that’s the same thing. It has a spark of life in it, but it doesn’t mean some big guy up there switched the switch.” The interviewer asked what he thought happens when you die and he answered: “our bodies start decomposing, then that’s it, we just switch off”. However he concluded by saying “I might be pleasantly surprised, who knows.”

Finally James was asked what he would tell anyone in a similar situation and he replied “get your ducks in a row as quickly as possible” and clarified that this meant the paperwork, so that “you’re as tidied up as possible.”

At this point the hospice nurse arrived and spoke to James’ friends. The interviewer concluded by thanking James for his time and energy and he hoped that he had helped her studying and given her something to work with. He said “I’ve got nothing to lose and you know it’s a different viewpoint. I think everybody has a different viewpoint.” When he was asked what it was like for him to talk like this, James answered: “You know, if this had been a month away or six weeks ago, I don’t think I could have talked. But now I’ve accepted what’s happening so I just get it out and talk.” He believed that the biggest thing that had helped him accept where he was had been the discussion with the Hospice doctor when she “put it in a nutshell”. “She explained and she drew pictures and said this is not years, this is months maybe even weeks. So

let's get you on some medication, do the palliative care, make it as comfortable as possible for the time remaining." And this doctor did so compassionately.

James felt that "in the back of your mind you always know. But it just takes that trigger to turn it over." He said "we all wish for a miracle and believe me if … I suddenly work up some morning and I felt, jeepers I feel great! What's going on here! I'd be running along to go testify. But I think the reality is that it's not going to happen so you just go from there." He continued that he was just taking it "day by day, minute by minute".

G.5 Paraphrase of interview with Keith

Case summary:

Early in 2004 Keith (50) went to his GP with a what he thought was an abscess in his right jaw; however, after a biopsy and CAT scan he was diagnosed with cancer of the neck and head. His doctors suspected that this was a secondary malignancy but did not find any other cancer in his lungs or internal organs. At this time he was given between two to six months to live. A Hospice doctor encouraged him to have a course of radiation treatments towards the end of 2004, which shrank the growth somewhat; however his cancer is not curable.

Keith's wife had been killed in a car accident two years prior to the interview. There are two children, a daughter of twenty-eight and a son of twenty-two; together with his girlfriend the latter lives with Keith. Keith is trained in appliance repair, but is currently unemployed; he is on his daughter's medical aid.

He was interviewed at home on 4 March 2004 at which stage his tumour appeared to be fairly slow growing. Not long after this, Keith had all his teeth removed as they had gone black from the radiation. He died on 26 July 2005.

Paraphrase of interview:

Keith said he had first become ill early in 2004 when he thought he had an abscess on the right side of his face. His GP sent him for an examination with and ear, nose and throat (ENT) specialist who recommended a biopsy and a CAT scan. These tests revealed that Keith had cancer and he noted that "after the biopsy it really started growing" right up the back of his head behind his ear.

Further tests were recommended, as doctors did not believe this was a primary cancer; his lungs were x-rayed but they were clear. He went on to say that his blood pressure was high and he was "drinking a lot because of problems I had". The doctor wanted to "put that pipe down my throat, but I'm dead scared of anaesthetics" Keith explained, so they gave him a barium meal instead. When the interviewer asked for more details, Keith stated "my daughter knows more".

When Keith was wheeled into the doctor's consulting room after this procedure, he told Keith that he could have chemotherapy and radiation but that these would give him "an extra month of hell!" "He said I might as well go home, he said I've got two months left. He said – enjoy your life! Go smoke, go drink, enjoy your life. He said two months, he said and then you'll most probably go into a coma … and die." Keith thought this was "honest". This doctor had suggested getting a second opinion, which Keith's daughter had organised. The second doctor said "no I can't say two months, it could be one to six." However, he recommended that if Keith wanted to go to the coast to see his brother, he should "make it soon", and told Keith to phone Hospice.

Keith said he had been getting thin, but when the Hospice nurse came she gave him morphine and other medication and he excitedly said he started putting on weight! The nurse recommended he see a Hospice doctor, who suggested a radiation oncologist. After a course of ten of radiation treatments "to ease it", Keith spoke enthusiastically: "all of a sudden it changed! It was shrinking!" He then had a further eight treatments with a specially designed mask. When the interviewer asked if the tumour was still there but smaller, Keith replied, with his hand under his chin: "something's here but I don't think this is it". However, he said his throat was sore and he was getting headaches again.

The interviewer noted that Keith had experienced a rough last year, he answered: "I didn't think I'd see my birthday when I turned fifty". This event took place in August. "I was still alive (he gave a little laugh) and then Christmas! And I'm still alive now." Keith said he had been shocked at the diagnosis and that it was "very scary". When asked how his family had responded, he said "I don't know. I tried being … no. You know. But I don't talk to them about it. I just try act like nothing's wrong. I've got nobody to talk to." He explained that his mother was deaf and talking to her meant shouting; the interviewer had met her as his mother was helping in the house at the time. He had two children, a daughter of twenty-eight and a son of twenty-two who lives with him; however he could not talk to them. He continued: "sometimes you just wish a person could talk about, you see?" He immediately said the doctor who gave the second opinion had told him he was likely to have a stroke, but this may not kill him and he may have many strokes. When the interviewer commented that he did not know what was going to happen, Keith firmly said "No! I'm getting

better!" He proceeded to inform the interviewer that many people were praying for him and that the radiation oncologist was very good. He thought the growth under his chin was "something else" that was making it difficult to swallow.

The interviewer asked whether Keith had any thoughts about what had caused his illness. He replied "my fault" and explained that his sister-in-law thought that when people got AIDS it was their fault, which was not the case with cancer. He disagreed with this opinion and told her so; however, he was sorry about this, as he remembered her son, his nephew, had died in his early twenties of bone cancer. "It's *my* fault. If I'd lived the life that I'm supposed to, that I could – not smoke, not drink, not do this, not do that. What's happened to me is my problem, my neglect. (pause) So I can't blame anybody else except myself." However, he went on to say that "none of us do really".

Then Keith said that when he went to the oncologist and he saw "other people worse off. …. You see these young ones and you think why am I getting better and they not? You know, then you feel guilty. Why me? Why am I getting better and not them?" He thought he was better off because he could still get around: he takes his mother to the shops and helps his son who is a builder.

Although Keith does not go to church regularly himself, he had found it helpful that people pray for him. He prays for everybody and for himself to get well: "you worry if you go then what's gonna happen here?" He was particularly concerned who would look after his mother: "My kids say they will but I don't know." He also felt concern for his son; he would not describe them as "close", and said: "we used to fight like cat and dog. But I love him, he loves me." However he thought his daughter would manage fine without him; she looks after him and got him medical aid. Keith added that he used to be on his wife's medical aid but she was killed. He said this had also been his fault. Someone in his brother's family had died and his wife wanted to go to the funeral. They had driven through the night down to the coast, and at some point when his wife was driving "I feel asleep in the car and when I woke up I thought we had stopped at a garage but when I looked there wasn't anything on the side of the car (he pointed to his right). A truck had hit us." He still did not know whether his wife had fallen asleep at the wheel or what had happened. When he got out of the car and walked around he could see that "there was a whole piece of her head gone (putting his hand on the right side of his head). So I tried to wake

her up and tried to stop cars and nobody … it was miserable." He believed this would not have happened if he had not wanted to go to the funeral.

The interviewer suggested that perhaps this horrific experience and his loss had tempted him to drink as he had said in the beginning of the interview. Keith said: "I don't drink get drunk you know … it's not that I drink so I don't think any more. It's a dirty habit." The interviewer commented that his wife had died a year before his cancer was diagnosed, and asked what had gone through his mind when he was told he maybe had two months. Keith replied: "You go blank. I just said thank you … and I walked out. And then you cry. You try not to but you do whether you like it …" He went on to say "but like I said it's getting better" and that he had been told that "some people live twenty years with cancer". When asked what he felt about the doctors who had given him his prognosis, Keith said "Nothing. That's what they thought; they were honest. I think it's better than telling you a whole lotta lies."

Keith was asked what he wanted to do with the rest of his life and he said that when he was feeling better he wanted to get work. He explained that he had been a typewriter mechanic but, laughing, said there were no typewriters left. He was able to work with vacuum cleaners as well, but that would not make enough to live on. In reply to a question about whether being ill had changed things in his lie, Keith said he looked at things differently: "Because if you know you're gonna die you start thinking about what's going to happen when you do, who's going to look after things."

He said that when he dies "I think I'll go to heaven. … See my loved ones in heaven… just hope I'm good enough to get there." He admitted that after his wife died "you think of killing yourself a lot" but he was too scared as "'I most probably mess it up". However Keith said he wouldn't commit suicide as he didn't think it was the right thing to do but, after his wife's death, "you think it would be better to be dead. But I think it would just make it worse so I really try … I do try. But if it's my time then it's my time. It's not up to me to say it." He believes "it's all planned out, by God." Keith thought he had been given a second chance several times, the first of which was a bad car accident a long time ago. He showed the interviewer a large scar on his arm and said this was full of pins and plates and that both his aorta and lungs had been leaking. He had hit the back of a stationary truck and, luckily, his seatbelt had broken and

he had slid down, or else he would have been decapitated. Although he said he did not feel needed, Keith felt concerned about how his family would cope without him.

The interviewer summarised that his concern for his family, his faith and his belief that he had been given these second chances for a reason, kept Keith going. He agreed and then described what he had been told about how his cancer might develop: “They say to me that this is going to burn my throat away … and um they’ll have to put pipes in my chest to help me breathe.” He noted that his throat had been very sore during the radiation treatment and he could only eat yoghurt, and that since the previous week his throat had been very bad again. His head was bad at night and it was uncomfortable to lie down as he could only sleep on one side; he was unsure whether to contact the radiation oncologist about these symptoms as his next appointment was the following month. When he can’t sleep Keith goes to “sit outside and go lay on the grass outside and look at the stars.” He finds them beautiful.

Keith would like to tell other people in his situation “never give up”. He said: “In the beginning I did give up – I thought the doctors can’t be wrong. That’s why I was getting very thin and very thin. …. I don’t know what the problem is with eating. It’s just in your mind. You run down. You don’t want to do anything, you know, you just want to lay down on your bed.” He then returned to the subject of his first bad accident when he had been in hospital for six weeks and had to learn to walk again, and had worked hard to regain the use of his hand. Keith then pointed at his cat, which had just walked into the room: “Ja look how my cat’s doing with three legs… he can jump and catch things.” He discussed his collection of dogs and cats, which included strays that needed a home and animals that were going to be sent to the SPCA and destroyed. “And that cat when he came crawling in here with tears in his eyes. I could have told the vet to put him to sleep and the vet said to try and fix it wouldn’t work (the leg). … but look at him, he looks perfectly healthy doesn’t he?”

The interview concluded with the interviewer thanking Keith for sharing his story and he said he hoped it had been helpful but “it’s not much of a story”. After being reassured Keith said: “I’m just glad I didn’t waste your time”.

G.6 Paraphrase of interview with Moira

Case summary:

Moira was a fifty-two year old woman who was first diagnosed with ovarian cancer at the end of 2000. Despite surgery and chemotherapy she had almost annual recurrences after that, until late in 2004 when metastases were discovered. She had further surgery but decided not to have more chemotherapy.

When she initially developed cancer Moira was married. However, there were difficulties in the marriage and she and her husband were divorced in 2002. Moira had two sons and a daughter, aged 27, 24 and 21 respectively. She was a primary school teacher and worked throughout her illness.

Moira was interviewed at her sister's home on 18 March and died there on 14 April 2005.

Paraphrase of interview:

Moira explained that she was diagnosed with ovarian cancer in November 2000 and had both ovaries removed and a complete hysterectomy, followed by what she described as "a course of six huge chemo's". When asked how she became aware that "something wasn't right", Moira said: "well it was actually very sad because I became very anxious because my husband was I thought having an extra-marital relationship and he kept denying it". This was particularly difficult as the woman concerned was the mother of one of the children Moira was teaching. She believes that this stress caused her cancer "101%". She became "aware of it and I became aware of two large uncomfortable feelings on my tummy … and that was the ovarian … so it was a sad experience."

She described becoming more and more anxious as her husband continued to deny her accusations that he was having an affair, so she went through chemotherapy "knowing that there was something still wrong". A year later, at the end of 2001, her husband left without explanation and "that put me into another bout", so she had more chemotherapy. Moira said: "this chemo is the

most amazing thing. I've regarded cancer, and this is really the truth, cancer and chemo as a gift from God. But the divorce has been the problem that I've got to come to terms with. It's not the chemo, it's not the cancer, and not dying. It's the divorce." Moira elaborated: "It's very hard to get rid of that terrible pain of a divorce" and said "it was a perfectly beautiful home".

However, she continued that she was now experiencing her fifth bout of cancer, which had been detected in November 2004. Prior to this she had been very busy, with a full-time teaching job and a remedial teaching practice at her home in the afternoon, "so I had to keep my head above water"; she believed she had managed this until the recurrence in September when cancer "reared its head again". These recurrences had generally been picked up through a raised CA, a tumour marker in blood tests. However, now it had "mastisised" (sic) and she had chosen not to continue treatment with the oncologist: "I've given my best of chemo and I've given my family my best and with my family's blessing they are very happy that I'm just living a good quality life now, with, and I don't have any pain whatsoever". She was trying to go back to school again and was "just going to live the way it's meant to be".

Moira disagreed that chemotherapy messed up her quality of life; instead she said "it was my best friend, it was my best friend". She explained that she thought living, dying and illness were about your state of mind and "I just so desperately wanted to live and give quality to my kids". Her three children are all in their twenties but she wanted to give them "everything that a beautiful home gives". She said she had "run in" to have chemotherapy, always feeling "excited", and had never missed a day of school although there were some days when she felt "a bit yukky". Moira added that she had received a lot of support from parents, teachers and children. At present she was teaching Grade 0 in the nursery school "so that gave me all the love and support that my empty tank was carrying around". She emphasised that "for me chemo is not that dread. I tried to do so much ministering to people to tell them not to dread it, rather take it as a blessing". However she had now "had enough" and was no longer strong enough "in my mind" to take chemo again.

Moira continued to emphasise that each recurrence of her cancer was stress-related: "like it was the suspicion, then him leaving the home, then he took my daughter away to live with him, which was a *major major* stress to me!" When

she described her feelings she said she felt “it’s not bitterness, it’s not anger, it’s um from the rejection is such sadness. And not only for me, for my stunning children who don’t deserve this.” She emphasised that she believes in marriage and not divorce.

Moira expanded on her confusion: “I didn’t know what I was dealing with first. Was I dealing with cancer and my illness first? Because if I got terribly upset, then family and friends would say but the watch the cancer. Then I deal with the cancer and become, but are you dealing with the divorce? It was a very vicious circle and I think I was caught in this wheel of torture. And I don’t know. I don’t know.”

When the interviewer suggested Moira had experienced loss, she agreed emphatically “*Tremendous! Tremendous!”* She said she had lost her home, before qualifying that she had sold it and she believed that this had caused the September recurrence, as it was “the real finality of our beautiful twenty-seven years of marriage”. She summarised: “so there’s been loss right since 2000; it’s dealing with loss every time and the loss just becomes more and more difficult to deal with.”

Moira said her kids had been “very up and down” with her illness and she felt anxious about this. She described herself as “the barometer wherever I go”. If she felt well, everyone was happy, if she did not feel good, everyone became anxious. “So I do feel a bit of stress and pressure on myself” to pretend. Moira went on to say that she is “very intense with very intense relationships” which help to get her through but also mean the house is always full of people and it is tiring “to continually be fine”. She said she was not fine and wanted to be in her own home, not with her sister. However, they were concerned that she would not take care of herself if she was at home alone, as her children were away.

When asked more about her children, Moira said her daughter was only fifteen when the cancer was diagnosed and that she had been “manipulated” by her father and only now was “coming right”. She said the boys “come to the party amazingly with their mother”. Their sadness was that “they want to show you their marriages, their children, their business, their cars, their achievements.” It

was different for a daughter “who wants you there more for her emotions, and for carrying her stably.” She said it was “not an easy path”.

The interviewer commented that the boys wanted her to see their future and Moira said: “I feel I don’t have a future, I don’t have a hope because it’s no good even going and buying another bunch of flowers because who knows how long it will be. But I think I’m coming more to terms with that. Death and dying is not a sudden realisation, acceptance and move on. It’s back and a fore, a back and a fore …” She was helped to move forward by “knowing that I’m on this earth for a reason and my time is up when He calls it not when I call it.” Moira noted that when she had her second operation, in January, “they didn’t give me more than a few days”. Instead she had “had eight weeks, which is two months” and this had been pain free.

When the interviewer asked about the spread, Moira said: “in the abdomen, but I don’t want to know. I’ve chosen, I don’t want. It doesn’t matter to me where it is.” Her second operation had been an ileostomy, which required a little bag than she was managing fine. She emphasised that God “makes and He takes … despite my will”. Moira then related in detail an encounter with a woman who said she had dreamt about Moira and God had told her to give Moira a message that she was going to be fine for a long time still and that God was there with her. Moira emphasised that she had been a Christian all her life and her faith was essential: “I couldn’t do this otherwise. Because when I get so low, what else is there to turn to?” She said: “I was brought up in a Christian home and that’s why I think that my divorce was so hard because I was brought up in the most beautiful home and it’s foreign to me. I never thought that men drank or didn’t work or had affairs or … I had to get to 50 to realise, well 48, I was 48.” She felt faith and the correct counselling made things easier. She had experienced both good and bad counselling through the church; however her best counselling had been the single session she spent with one of the Hospice social workers who worked through the dying process. She had now been able to work other people through it too. She had realised that “Hospice is not what we all *fear*, the same as chemo.”

Then Moira asked if the interviewer had been to a room where chemotherapy is given, describing it as “beautiful” and “a wonderful place”. The interviewer revealed that she had had chemotherapy after breast cancer. Moira asked if

she had a reconstruction after mastectomy and then said the same plastic surgeon had “made an *absolute* disgrace of her daughter” when doing a breast reduction, so this needed to be redone. She repeated, “this has been a hard walk for all of us. But you know I’ve had a wonderful youth. I had a wonderful marriage. I’ve got wonderful children and family and friends. If God wants me, He must take me. Obviously I’m finished with my work here. I’m very aware. I’m not of choice ready to go but I’m not fighting. I’m not fighting. Every day I wake up and I think another day I’m here”.

Moira emphasised that she had no pain. Although the hospital had wanted to give her a morphine patch in January, she had “begged” them not to, as “I wouldn’t have been able to talk properly and live properly if I’d been gaga on morphine.” She was going shopping after the interview and was not “sitting around wasting time”. However, she admitted that she needed to be careful as her “nature is very much up and go” and “conquer”. Moira commented that she had not been able to control either of the “two sadness-es in her life, divorce and cancer”. She wanted to “make closure with the divorce” but her husband would not communicate with her: “I can’t make closure with the sore that’s actually ripped open and sitting waiting”. Her husband would not communicate so this sore “still sits open”.

Moira noted that unlike her husband she had not “made another relationship” and joked: “if I want another husband I’d go and buy my own Audi (laugh). To talk about your Audi.” She believes that a lot of women lose their husbands when they had cancer, as men cannot cope: “A woman will stay with a man no matter what. A man doesn’t necessarily stay with a woman.” And she continued: “I think they’re weak. I think they’re scared. I think they are egocentric and I don’t hate men. I think they are selfish, very extremely selfish ... can’t deal with the realities of life.” She had not believed her husband was selfish in that way, and had been surprised that he had left her when she was sick. Moira said her oncologist had noted that “the men don’t stay, they get out”. She hoped she had taught her children not to do that as “we marry for better and for worse, in illness and in sickness” (sic).

The interviewer asked what triggered the back movements in Moira’s process of coming to terms with dying. She replied promptly: “fear, uncertainty, lack of control, lack of power, fear of loss, not fulfilling dreams in my children,

disappointing my family. I've still got two parents alive. The order's wrong." However, she considered it possible that dying now was removing her from the "extreme" emotional suffering she had been experiencing. "I loved my home, I loved my marriage, I loved wearing my ring, I loved it. I just believe in marriage!" When she thinks about this and her children no longer having parents who were together, she goes backwards.

Moira explained that she had written a nine-page letter to her husband and had kept copies for the albums she had made for her children. She said: "I talk very openly about death and dying. … it's not a big-C, it's cancer and it's chemo, and it's death and it's dying and it's loss and it's funerals and we talk openly." However, she did sometimes have bad days. Her last two downers had been after being away for the weekend, and she may have been too busy. The Hospice nurse had given her anti-depressants, which were very helpful. She had also found the Hospice counselling good, which had not been the case with other places, including at times the church.

Moira hoped that her experience of dying and talking to people about it would make a difference for others, although she found talking about it a strain. "And dying is not fun, and dying is not easy. But it's steps, and once you're going those steps you come to realise that you can do it. Have to do it. Got no choice." She explained: "I'm not scared of dying. I am, I was and maybe I still am, anxious of the means to die. Will I be riddled with pain? Will they be able to control my pain? How will I be emotionally? How will the people around me be? Where will I die? How will I die? Who will be with me? All those questions of the uncertainty and the unfamiliar." When she was asked how she would like it to be, Moira answered with an explanation of the dying process she had received from the Hospice social worker, involving become more and more tired and withdrawing from life, which she described in detail. This had made her feel better because she thought the portrayal of dying on TV and in the movies involved a lot of frightening "*hype*!" She wished that Hospice had better coverage and that programmes on TV talked more about how death "is going to come", "because we don't talk about that. We need to talk about it because there are millions out there that need to know it's going to be OK because it's a dead cert – you're going to die." She believes most people fear "the death of cancer".

Moira would prefer to die here at her sister's house and she had everyone's permission for that. However, she was also happy with dying at Hospice if things got difficult; now that she had seen it she would be fine, and there could be an extra bed in her room for a caregiver, child or friend "to sleep there with me all night". She felt that she did not want to die yet as she still had things to do, but she was no longer scared of it. "Just keep me without pain because that's the biggest blessing that there is that I have now."

When asked if she had regrets, Moira again spoke of the break up of her marriage. "I'd marry him again tomorrow, the man he was. But not the man he became." Her children kept asking if there were places she wanted to go but she just wanted "to be with my kids and family and friends". She repeated that she just wants "to be". "I would love a future, but I realise that too many of us think our future is in the gaining of possessions." She had spent the weekend away with friends who had gone to a gift shop and been "anxiously buying, frenetically buying things". She had not wanted to buy anything, although she used to be materialistic like that herself and focused on gaining friendships, money and possessions but thought none of this meant anything when "the chips are down". Instead, life was "to do with interpersonal relationships, it's got to do with love and care and support." She felt people spent too much time rushing around and getting upset over insignificant things, like where their children leave their shoes. However she realised it was not that easy to stop or change.

After dying, Moira said she knows "I'm going to the next world. He promises that. And I'm holding onto that." She has faith and believes that God has helped her through the last five years, and particularly through the eight weeks she has now lived when she was expected to die in three or four days.

Moira admitted that if she were in her own home alone she probably would lie on her bed all day and not eat well. She said that she had not fed herself properly in the last few years because she had been so depressed and lonely. Again she emphasised: "don't *ever* unless it's essential get divorced. It is the cruellest thing that is ever on this earth." She described being depressed as "that surface is too cold and too sore". Her mood had now lifted and she enjoyed being 'still useful' e.g. fetching a child from school and helping with dinner. "I'm not sitting around with nothing to do like a blob."

When asked whether she thought her husband was avoiding her because she was dying, Moira said that when she died, "'he's going to get a terrible, terrible shock. And I think it will bring it, the guilt close to his surface… and I think that if he saw me it would be too much for him". She explained that he had lost jobs and been demoted and his ego had taken "a terrible bang" and her lawyer had taken him "to the cleaners so financially he is in a bad place". She felt this was not her fault but his, as he would not communicate with her or her lawyer and just signed things away. Although she wanted him to tell her why he left her "he has behaved so badly I don't think he can afford to see me". Moira believed he would never manage to develop a good relationship with his children again "when basically you've been involved with the cause of your mother's death. I don't think they ever get over that. But that's not for me to sit and judge".

The interviewer commented that this was an incomplete that was worrying Moira and asked if there were others. She replied: "I've sorted it all out! Got the will up and going, I've sorted out my home, I've given it to my children. No I've got it all sorted out." There were still various letters she wanted to write but if she did not manage to do so it did not matter; she was complete with everything and everyone except her husband. Moira did not think "I've looked in the face the extreme of the illness" but this did not matter. Her children had approved her decision not to have further chemotherapy and had encouraged her no longer to wear a bandana on her head to cover her hair loss; they wanted her to be "normal and natural". Moira said about the cancer, "it doesn't really matter what the stage is. I'll go with it as it goes. It'll just take its course and I know that the doctor is not God either! It's been proved. Because he just gave, he didn't even think I'd come out of hospital. And it's been eight [weeks] very full of quality life."

After the interviewer had thanked Moira for giving her time when each hour was precious, Moira said: "I'm not overboard with that. I think I still haven't got to that stage. I don't know that I ever will. I know everything is of value but that's also life. I'm not the only one that's dying; I'm not the only once that's in a bad place. And I'm probably in a better place than millions others who're lying in a tin shack with nobody around them, not even a painkiller. And so therefore I try to appreciate things".

She hoped the interview had “been of use to you in any which way” and asked about other people who had been interviewed and whether they had thought the same as she did. Some discussion of this followed. Moira felt the word “resigned” was appropriate for her. She emphasised that her “cancer has been a joy. And chemo. Been a joy” because she had met amazing people. She joked: “I don’t know if you ever read that book called um The Apache Syndrome – a patchy hair here, a patchy hair there”, and both laughed. She didn’t “want to go … I’ve got lots to still do and conquer with my kids and my friends.” However, “it’s a killer, cancer’s a killer”.

Moira and the interviewer discussed chemotherapy further and the way it “plumps up the wrinkles”. She asked about the interviewers check-ups and told her she had gone from “absolutely nothing to just everywhere in one matter of two months”. Moira asked if the interviewer was scared of dying, how her parents had dealt with her cancer and encouraged her to create more publicity for Hospice. After this discussion, the interaction finished with the interviewer wishing Moira well in her journey and hoping the end came the way she wanted it to.