

APPENDIX 5

Transcript of Patient Interviews on the Video Disks provided with this report in DVD and Windows/Mac compatible format

We asked five volunteers who had originally taken part in our survey for the Report to talk about the experiences they had had during their illness. Their comments cover the diagnosis and treatment phases of the illness and also their experiences following discharge from hospital. The views expressed are relevant to the content of the Report but are not part of the formal audit findings. The intention is to provide personal insights into the subject matter of the Report, additional to the statistical and other analysis. The National Audit Office expresses its considerable thanks and gratitude to the people who took part. Interviewing was carried out in February 2005 by Origin ID.

Diagnosis

Andrew: Hello my name is Andrew, I'm a 57 year old widower, and I've been dealing with a prostate condition since 1995.

Carol: I'm Carol Adams, and two years ago I was diagnosed with colon cancer, which then subsequently spread, to my liver.

Judith: My name's Judith Broadbent. I've had a number of illnesses and I've had 17 operations so there's, I've got quite a history of things. But probably the most traumatic illnesses that stick in my memory most are that I had breast cancer twice.

David: My name is David Rixon. I'm 67 years old, retired. I was in the meat trade for many years. I had no symptoms. I had read a lot of publicity about prostate trouble for men of my age and went along for a check up.

Barbara: I'm Barbara Alexander and about 18 months ago I was diagnosed with bowel cancer.

How were you told the news?

Andrew: I was on my own when I had the news broken to me, I was sort of semi-expecting it because I had the two sets of biopsies.

Carol: By that time I was with a colon specialist, told me the probability although they didn't know until they operated. He then told me as arranged actually he telephoned me because I wanted to know before the Easter bank holiday and I had a very sympathetic phone call at an arranged time when he'd been able to analyse the matter just before Easter. So it was done in a way that was agreed.

How were you told the news? continued...

Barbara: I went to a consultation at the hospital and I was told but I was well prepared for it because in the end it was confirmation of what people had thought for quite some time really. So it was fine.

Judith: You know immediately it's bad news when a huge number of people walk in to the room so I knew immediately it was bad news - and that it was breast cancer again and I had to have a mastectomy.

How did you cope?

Barbara: I coped in two ways. I coped in the sensible way in that I tried to stay rational and focused and ask questions. But then there was an irrational response which made me think that I was going to be dead in two weeks and all the things I've got to do before then. There were two sort of strands to it.

David: I never thought of it as terminal I just thought it was another nuisance of getting older. They did tell me that it was borderline and I read that if it's treated early, the old cliché is that more people die with it than die of it. I hope that will be the case.

Judith: The first time I was told I had breast cancer I was very, very upset because I was a lot younger, I was ten years younger and I assumed I was going to die. I just didn't know anything about, I didn't know anything about cancer it was a bolt from the blue first time. Second time I was not surprised because when you get a lump it seems its cancer.

Andrew: First of all when you are told you have a cancer I think you realise that you are a mortal being, and that is quite a big thing to take on you go through life and you think you've got no problems, but coping with that from an emotional point of view, as I say I think I became proactive, that is how I dealt with it, let's get on and deal with it, and let's find out as much as I can about the condition and the ways forward to treat it and that's how I personally coped with it.

Carol: I managed to be extremely positive. I wasn't devastated. Or saw it as something to be as a challenge to be dealt with and to try and overcome it and to draw on all the resources available to give it my best shot.

How did you deal with telling family & friends?

David: The family obviously knew that I was going, I didn't keep any secrets. You know, we're a close family.

Carol: I told everybody very honestly at that stage what had happened. Although at that stage I hoped very much that I'd recover and be 100 % fit afterwards. So yes I told people and that brought enormous support.

Barbara: That was the most difficult for me. I had to tell them before hand because leading up to the diagnosis. I'd needed help because certain tests I'd needed to have I had to have, I had to be looked after overnight afterwards so I couldn't cope on my own.

Andrew: My mother was very ill and very sensitive and I'd just lost my brother at the time as well through another illness and I couldn't really break the news to my mother directly and so I had to confide in my other relatives, my sister-in-law and other people were aware but I didn't want to trouble them too much because of all the other issues that were taking place at the time. It was quite difficult but I did have the support of a close friend.

What support did you get from family & friends?

Barbara: I had excellent support from both my family and friends.

David: We're not a particularly emotional lot. Support was always there we didn't discuss it very much – we were more worried about not missing the appointment.

Carol: The phone never stopped ringing, people visited, work colleagues were fantastic, my work was very good and supportive in my absence. And people were wonderful actually.

In Hospital

Please describe your first experience of treatment in hospital.

Judith: I have found my experiences as a patient in hospital have always been very satisfactory. I've never had any complaints or any particular questions about surgery or anything. The worst, the thing I found most difficult about being hospital is that everything happened so very, very slowly. So the doctors come around at 8:30 in the morning and then almost nothing else happens all day.

Barbara: As an inpatient that's when I went in for surgery and I was very well prepared for that and I went in very calmly and I had confidence in the people and in the whole hospital really so it was very positive. In so far as it could be positive.

Carol: I was part of a ward of many, many women waiting for scans for all sorts of aches and pains and yet if someone had put together the history of what had happened to me and the tests that had been done and the nature of my pain I think I should have been with a colon specialist much earlier. There doesn't seem to be a good system on admission to hospital for streamlining getting you to the person who can put together the various symptoms.

Andrew: When I went to hospital I was sort of admitted by a series of locum doctors or agency staff, and obviously they weren't aware of the history that I had, and so that was a bit difficult to understand that all that they were doing was actually admitting you to the hospital and doing the necessary tests, but I was reassured a bit later on when I actually did see the consultant, and he talked me through the actual procedure again that I was going to be involved in.

Can you give examples of how you were informed and involved in what was happening?

Barbara: Everything was explained to me and I was allowed to ask questions which were very fully answered.

Andrew: Actually I had to make big decisions at the time, because I was given the option of treatments and obviously the surgeon wants to carry out surgical work, the radiologist wants to do radiotherapy, and so I have to be, I was involved in that decision process luckily enough I sort of had enough control, because another factor when you are told that you've got cancer is that you feel a bit out of control.

Carol: Once I was in hospital all of the discussion and information sharing and all of the treatment was excellent. Once we got to a diagnosis I was made fully aware of all of the issues the likelihood of treatment I was asked if I had any questions.

What support did you get and what was most helpful to you?

David: I didn't really feel that I needed support in the hospital. It was when you go in there you couldn't, I always thought this with the National Health, minor things you have difficulties but when you've got something seriously wrong I found them extremely good.

Andrew: One particular nurse that sort of did take an interest was an old trained National Health nurse who was actually working as an agency nurse, but I did have some kind of bond with her, and I managed to talk of the emotional side of the actual illness and I found that she provided quite a good amount of support at that time for what was happening, and she had the experience so she knew exactly what the situation was with being a patient having this treatment.

Judith: The second time that I had breast cancer I was with a breast support nurse. So she was someone that I felt that I could spend more time with because one thing that you never feel that anyone's got a lot of, is time and especially time that you can spend with your consultant is extremely minimal. The breast care nurse you felt that you could spend time with her and that she would understand when you were upset and so I'd splurge on about my concerns.

Barbara: The nursing staff were very expert and very attentive. They were very good and I felt I was being monitored the whole time. There was also sort of extra support because with my particular surgery I have a colostomy and I also had a pre-existing mobility problem so I needed a lot of physio and all that support was available.

How were you made aware of possible side effects of treatment?

Carol: I've had all the possible side effects explained to me not only by the oncologist but by the nurses who give chemotherapy. I found all of that information and discussion very, very helpful, very well informed.

Andrew: The actual side effects of the treatment I got most information for that from the actual hospital leaflets.

Judith: I was made aware of the side effects of my treatment by probably leaflets and explanations and by myself using the Internet and having a look at the drugs I was being given there or the procedures.

Barbara: The side effects and what I might expect as a result of the treatments were very well explained beforehand. Some I hadn't anticipated and one in particular which was the result of not eating and drinking for a very long time. But otherwise it went more or less as I expected and there weren't any nasty surprises.

How much did you understand about your condition and treatment options?

David: I understood as much as a layman could I think. I didn't really want to go into all the medical details as far as I was aware there was a small growth.

Carol: I had everything fully explained to me. Ever since the diagnosis I've found information is very good.

Barbara: I did understand all the implications I think because I'd thought about it a lot I'd researched it beforehand I'd looked on the Internet all those things. And people answered my questions and the thing that I most appreciated was that I was allowed to weigh up the options. They put them very fairly before me. I mean there's a limit to the choice you have in those circumstances but I did feel that I was involved and to some extent in control.

Andrew: At the time I fully understood the actual treatments that were available and the actual treatment that I was undertaking and I was able to discuss that quite in detail with the actual consultants at the time.

Judith: You're told lots of pros and cons but you are not directed into which decision to make. And definitely the first time I had breast cancer I really wished someone would just decide for me and I really wanted my consultants to say I think you should have a mastectomy or I think you should have radiotherapy, no one, no one did, so I had to make that decision.

Did you feel your views were taken into account?

David: I can say that I feel my views were taken into consideration particularly by the top man and all his deputies they were all extremely good. I'm sure if I'd said I don't want this breaking therapy I don't fancy radio-activity. In fact it's a bit of a joke in the family, radioactive keep away that was afterwards. But they went to great lengths to explain it.

Barbara: My views were taken into account because I was asked and I agreed to be part of a national clinical trial. And so I was given a lot of information and again I had consulted the Internet and I was allowed to choose that without any influence one way or the other.

Andrew: I did try to insist on one type of treatment which I thought was a better option and I had to go back and have a second test to see whether a course of tablets had allowed the actual prostate to shrink to allow this treatment to be carried out. So I sort of managed to achieve that and have the treatment that I particularly wanted at the time.

Judith: I always felt that my feelings were taken into account yes I think they have been very good at explaining things to me.

How involved were family and friends?

Barbara: When I was in hospital my family and friends were involved as much as I wanted them to be and as much as they needed to be. They were allowed to visit. People spoke to them and explained to them but actually most of the time I was able to explain to them myself.

David: I'm inclined to think that if I'm happy with what's happening to me I'd rather leave it to the people who know what they're doing and don't ask too many questions. I would have done if I'd thought that things were going wrong. But the attention was very good if you wanted painkiller or anything like that it was always there. And it was a self contained little room even a private patient couldn't do better.

Was there pain? How did hospital staff help?

Carol: I did have acute pain after the operations. There are some difficult moments when you need pain relief in the middle of the night and the on-call doctor has to be found in order to sign the prescription. And I have had experience of having to wait several hours for that. That seems to me a system that could be improved in hospitals. I wasn't in life-threatening pain I was just in acute postoperative pain.

Barbara: The pain control was something, which I hadn't anticipated. It was a very long time since I'd had major surgery like 50 years before I'd had major surgery. And this time I experienced really very little pain. It was very carefully controlled and that was all planned and there was a special pain control nurse who when it didn't quite work was summoned and everything was arranged yes it was put in order.

Discharge and Community Care

How did you feel about leaving hospital and going home?

Carol: In terms of leaving hospital I've never been able to wait to get out of hospital. I was always very fit and very ready to leave hospital. I found that process very good actually after three operations. As soon as I was fit and able to manage food I was sent home I was never kept in hospital an hour longer than I needed to be. I had a very good recovery. So I found that very satisfactory.

Judith: I've always been delighted to leave hospital and go home it's never been a concern to me. I can always manage by myself pottering about. Friends and neighbours have done bits of shopping for me.

Andrew: Leaving hospital was okay in fact I couldn't wait to get out to have a good nights rest really because it's very noisy in hospitals and it was very nice to be discharged. Although, the discharge process involved quite a lot of delays and waiting for the actual consultant to come around and allow you to go home. But apart from that that was fairly straight forward and I was taken home and supported by friends and family at the time.

Barbara: I felt fairly confident because they had kept me in hospital probably 3 or 4 days than is usual or probably longer than they planned to do because I needed a bit more care I needed more time to get mobile than I think they probably realised. And coming home then I had one of my family came and stayed with me for a week and it went well. But I did need a lot of care when I came home there was very little I could do for myself.

Did anyone inform you about support groups?

Carol: In terms of support after the operation I had a lot of support afterwards, complementary therapies, access to nurses but the thing I've most valued is the relationship with my GP which has been about total availability and willingness to speak to me and be helpful at any time.

Andrew: I wasn't informed of any real support groups and I think that's quite important to be able to talk to other people in the same situation I think that it's really important now in hindsight. You really get so much from talking to people, or I do now, who have had this particular problem. And at the time there was no information or very little information or very little information about support groups.

Judith: I'm sure there are breast cancer support groups but I wouldn't want to join one but I do like knowing that there's a breast care nurse that I can ring if I've got any worries.

At home did you get any support?

Barbara: When I came home there was follow-up support from district nurses who came often. And also for the stoma support nurses whom I'm still in touch with I have a telephone line and they give me ongoing advice, advice about new products because that something I have to live with all my life so that very valuable.

David: Talking about support afterwards. I was informed about support groups but all of us are a rather solitary people and I'm sure if we'd ever wanted it we could have gone to it but and financially fortunately we're okay but they were mentioned and we could have followed up if we'd needed to.

Did you find anything out about financial benefits?

Judith: Financial benefits have never been applicable to me. I've always just been off sick for a while and my employers have always paid sick benefit and then I've gone back to work full time with reduced hours and then full time.

Andrew: I wasn't aware of any financial benefits at all and I've actually, because of the information that I've received from the actual prostate cancer charity I've made a donation to the prostate cancer charity because they provide excellent information booklets. But I've not been aware of any financial support at all for my condition.

Barbara: Financial benefits I haven't looked into. I shouldn't think I'm eligible because of my circumstances. But I'm sure that if I had needed it and if I had asked the information would have been available.

Carol: In terms of financial benefits fortunately I've been in a situation where I haven't had any financial difficulties so it hasn't been an issue I've had to look into at all.

How did you cope with life back at home?

David: The problems we faced coming back home. The main one is passing water, whether that's to do with the prostate or whether it's to do with age I don't know. But you go for a check up and you usually end up talking to a particularly glamorous lady doctor with a particular one the first time talking about penile malfunctions! At first it's very embarrassing but after a bit she's not embarrassed so why should I be and you tick off the list.

Barbara: When I got home I recovered quite slowly physically but I'd been warned that it would take 6 months. And the help I needed I had. I mean I live in a place, which is accessible which I didn't get a feeling of confinement so much, which I might have done. It's difficult adjusting to your changed physical state and that something that you need to come to terms with and I guess that takes a long time.

How did you cope with life back at home? continued...

Andrew: Life back at home. When I came home I did have a problem after the actual procedure, which I was aware, could happen and did happen. I had to go back to the accident and emergency a week or so after the actual procedure, which happens to a small number of people. But apart from that, things have been going well and I've been managing the situation.

Judith: I think because I had a child to look after and no one else at home that always made me try and get myself as good as possible quick as possible and not be too maudlin about things and certainly not to be despairing because that would have been the last thing that he'd of needed...

What would you say to someone who has just been told they have the same condition as you?

Carol: What I've found quite interesting is talking to people friends who've recently been diagnosed with cancer and recognising them being at the stage I was in the beginning when you sort of thought you were going to marshal your troops and beat it. And just thinking that there's another stage of recognising that it actually can control you, you don't control it. And to many people maybe that is hard and perhaps it's that longer-term support that cancer sufferers need.

Barbara: To anyone else who might be in the same position I'd think I'd say that you should try to inform yourself to get as much information as you can and to review the options. And if possible not to fret too much about what are not options anymore. That's hard to do but I think the NHS has responded very well to me in that respect and that's helped me to cope with the whole experience.

David: If I was told that somebody had a condition I would say well get on don't hesitate because there's bound to be delays of one sort or another. My own operation was put back a couple of times and the warning is not to leave it too late.

Judith: I think if someone was diagnosed with those conditions they would probably have a fairly bleak outlook. I would be encouraging and I would tell them what to expect. But what you can't do is everyone's experience is different, everyone's experience of the same illness is different, peoples' prognosis' are different.

Andrew: I'd say talk to people. Talk to as many people as you can and find out as much information, there's lots of information available. Find out as much information as you can.

Carol: I think I would encourage them to really do all they can to overcome it and to believe that it can be cured but they mustn't start thinking in terms of this being fatal and how long have I got? That cancer these days is a long journey, there are new treatments coming on-line. And particularly if somebody's at the start of that journey they'll have different drugs and treatments to the ones I've had over the last two years. So I think I would encourage them to be optimistic but also to be realistic about it and to accept that you do have to have a different mindset about life.