

Bob Grant – a Scottish influencer

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This is one of a series of portraits created by Alison Donaldson & Elizabeth Lank for Macmillan Cancer Support, describing how Primary Care Cancer Leads in England, and their equivalents in Scotland, Northern Ireland and Wales, have influenced cancer care locally and nationally. These accounts are intended to stimulate learning by describing how a charitable organisation can work with doctors (as individuals and also as members of 'communities of practice') to make a difference to people living with cancer. We wish to thank Bob Grant for giving time to telling his life story and talking about his work and his relationship with Macmillan. Please address queries to jmaher@macmillan.org.uk or alison@donaldson.demon.co.uk

Bob Grant – a Scottish influencer

Bob Grant's life is an extraordinary example of how a person who has survived cancer and lived for years with the late effects of radiotherapy has succeeded in becoming a national influence on the Scottish cancer scene. Since the early 1990s, he has held various advisory and lead positions and worked continuously with Macmillan Cancer Support. Currently he is Chair of the Scottish Cancer Group and also part of an NCRI group looking at cancer in teenage and young people. He has drawn on the health problems he himself encountered from his school days onwards into a strong personal motivation to improve patient care.

Life-changing experiences

In 1960, at the age of 14, Bob Grant started to find it difficult to walk to school and his mother noticed he had developed a limp. Bob was told by the GP, who saw him on more than one occasion, that it was just growing pains. But the pains got worse and eventually, early in 1961, another partner in the practice helped his mother get an emergency appointment at the hospital. At the time Bob was told the result of his x-rays was "not good", but it was only much later that he found out that it was a bone tumour he had had – a non-Hodgkin's lymphoma in his thigh-bone (femur).

Bob spent several weeks in hospital in Aberdeen and Edinburgh and he recalls the hospital experience as "quite difficult". As he left to go to hospital in Edinburgh, the Ward Sister in Aberdeen took his crutches away from him and he was taken by ambulance to the station and put on a train without them. His "welcome" in Edinburgh was not much better, so he had two experiences of unsatisfactory care in one day. Looking back, Bob reflects that "a whole lot of attitudes were wrong at the time", and he hopes that young people receive better care today – especially with the development of special adolescent units.

In Edinburgh, Bob was in a ward with other patients with advanced disease, and yet he was never told he had cancer – his mother was anxious to keep the knowledge from him. (Years later, Bob was to discover from reading his primary care notes that there was "no great expectation of survival" at the time.)

After his treatment, Bob grew rapidly, but his two legs grew at different rates and he ended up with one leg about three inches shorter than the other. He was given a special shoe and managed well with it – skiing was the only activity he had to give up.

Bob had always been interested in medicine but his personal experience had made him "more enthusiastic than ever". Despite the time lost from school, he got into Aberdeen University medical school and graduated in 1970. About a year later, with the help of a friend working in pathology, Bob managed to check his own records, and it was then that he learned that his condition had been non-Hodgkin's lymphoma. It also occurred to him that he may have had a

higher dose of radiotherapy than would be normal today. As we know, radiotherapy can affect both blood vessels and the lymphatic vessels, and the effects can last for the rest of a person's life.

During the next few years Bob embarked on a career in surgery with a special interest in cancer medicine. He started with a house job in surgery in Aberdeen, and then moved down to Glasgow to focus on a particular type of cancer research. By now it was already becoming clear to him that general practice suited him best – his best six weeks as a medical student had been those he spent in general practice in Orkney. So when an opportunity came up to become a partner in a practice in rural Dumfriesshire, he took it up. After five very interesting years there, still keen to explore other career opportunities, Bob spotted a job in the radiotherapy department at Addenbrooke's Hospital in Cambridge, where he spent two years doing clinical oncology and research. At the end of this spell in Cambridge, he and his wife were keen to get back to Scotland. Eventually, in 1981, Bob settled into a two-doctor general practice in Fife, where he and his family have remained until today.

It was in 1988 that “completely out of the blue” Bob developed new problems with his leg. He woke up suddenly one night feeling terrible and shivering with a fever and was admitted to the local infectious diseases unit. It turned out he had septicaemia - the infection had settled into his bone at the tumour site and was affecting all the soft tissues of his leg. He was off work for several weeks. Despite the “superb care” he enjoyed in the old Hospital for Infectious Diseases, the problem was persistent. During the next few years, he had three major operations, but every time he came off the antibiotics the infection flared up again. By the early 1990s, Bob “was beginning to despair”. After yet another flare-up, in about 1996, he was put on high-dose oral long-term antibiotics and for a while his health picked up and was even “quite good”.

1990s: start of formal influencing activity

Meanwhile, in the early 1990s Bob embarked on his first formal “influencing role”. He was appointed as a GP advisor to the Fife Health Board. In this capacity, he developed an interest in acute services and enjoyed undertaking a survey of GPs' views of such services.

In about 1995, the Fife Health Board appointed another doctor, Sue Ibbotson, as a Consultant in Public Health. Bob describes Sue's appointment as “a breath of fresh air”. This was the time of the Calman Hine report (on the future of cancer services in the UK), which recommended the appointment of a Lead Cancer Clinician in every area. Sue Ibbotson suggested that Fife create a Lead Team, and she and Bob worked with St John Hattersley of Macmillan Cancer Relief's Office for Scotland and Northern Ireland (OSNI) to secure funding for it.

The Lead Clinician Team that was formed included John Wilson (lead clinician and gastroenterologist), Murdina McDonald (a nurse) and a full-time administrator, all of whom, like Bob, were Macmillan-funded. Bob himself was the first Lead GP for Cancer in the UK (his full title was Macmillan Cancer GP for Fife). The team enjoyed “fantastic backing” from the Fife Health Board,

which picked up the funding after Macmillan had pump-primed the posts. *“Anything we said was done – with the full backing of the Chief Executive.”* For example, Sue Ibbotson, working with the Chief Executive (Pat Frost) acting as Chair, succeeded in setting up a Cancer Board for Fife. The Cancer Lead Team were able to present their ideas on a quarterly basis to the Cancer Board and actions were consistently carried through as a result, recalls Bob.

Bob’s Macmillan funding gave him four sessions a week of protected time and he retained the Macmillan tag after the Macmillan funding ceased. His role as Lead GP for Cancer continued until he retired, while the administrator, nurse and lead clinician are all still there today.

Bob points to a whole range of factors that enabled the Cancer Lead Team concept to work “extremely well”:

- It enjoyed high-level backing and “ownership” by the Health Board executive
- It had its own suite of offices and full-time funded administration.
- John Wilson, as leader, was a “fabulous facilitator” and “kept the team together”.
- Bob himself had already worked as a GP advisor to the Fife Health Board, so becoming Lead Cancer GP “was not a jump, it was an evolution – I had all the right contacts”.
- Each individual brought distinct skills to the team. For example, Murdina was an important member from Bob’s point of view, since as a GP: “There was no way I could get into the nursing situation. We talked every week.”
- The weekly team meetings were crucial and could be used “to bring in other significant people.”
- Last not least, the team had excellent links with Public Health in Fife: *“Most GPs have very little contact with Public Health. We had some strong personalities in Public Health in Fife who could do things that I couldn’t. For example, they made the questionnaire [for the survey of GPs’ views of acute services] possible – it was a big task. Having a link with a strong public health department opens doors to a range of skills, certainly in Scotland.”*

Overall, then, the result was that the sum added up to much more than the parts.

Making best use of practice visits

While he was Lead GP for Cancer, Bob wanted to find out what GPs thought about existing cancer services and so he started visiting local practices:

“I found they were keen to co-operate and I got loads of information I wouldn’t have got via a questionnaire”.

Ultimately Bob visited every practice in the area – about 63 in total – a task which took just under two years. During each visit he scribbled down some notes and then, after the visit, went straight to the car and used a mobile

dictaphone to dictate a note. The typed-up note was then sent back to the practice in question, inviting their comments. Next, Bob finalised the note and, after every five visits, he collated them into a report, which he presented to the Fife Cancer Board at its next meeting:

“The collated visit reports drove the agenda of the Cancer Board, because we were picking up so many concerns. We were bringing information from practices that was unknown to the Board. This really did make a difference, and I could go back to see the GPs again afterwards to show action was being taken. For example, we learned that there were deficiencies in the urological cancer service, so we worked with the consultants and lobbied for an extra consultant in this field.”

While Bob was pursuing his practice visits, Sue Ibbotson was setting up “Specialty Liaison Groups” for all the major cancers. For example, there were concerns about the breast service at the time in Fife. Sue set up a breast group and Bob, significantly a GP and not a breast surgeon himself, became the group’s Chair. He recalls how, at the first meeting, he discovered that the breast surgeons from the two Fife hospitals hadn’t even met before, so he was able to introduce them.

“The breast unit in one hospital was shut down and all the services were focused on the other hospital. It was the only service in the whole of Scotland that changed radically during the period of purchaser-provider contracting. It had often been unsatisfactory (my patients were telling me of terrible things happening) and now it was producing among the best results in Scotland.”

The period when Bob and his colleagues in the Fife Cancer Board had their best influencing years was from about 1995 till 1999. After that, the political set-up and the relationships all changed, with the Chief Executive of the Health Board moving on, Sue Ibbotson moving away, and the Lead Clinician also changing. Once the political backing was lost, the Cancer Board became much less effective and people stopped turning up to meetings.

2001: leg problems return

One day in early 2001, while walking his dog, Bob fell and broke his bad leg. By July that same year he was certain it was not going to heal as it was a pathological fracture. After further investigations, in September 2001 Bob had a “massive distal femoral prosthesis” inserted. After the operation he was quickly walking again and feeling great, but once again after the antibiotics stopped he became very ill with a fever. He was flown back to hospital and put on intravenous antibiotics. It seemed that the only way was to stay on antibiotics indefinitely.

In February 2002, Bob tried to go back to work part-time but found it very difficult. So, after a whole year off work, he decided to take early retirement in July that year. Over the summer the leg felt heavy and tired but Bob tried to make the best of things and take a holiday in France. However, in October 2002 the fever returned – this time despite the hefty antibiotics. Bob was

admitted to the Infectious Diseases Unit in Dundee, where he received 10 days of excellent care. However, Bob recalls:

“One day when I looked in the mirror I didn’t like what I saw: I thought, if that was my patient, I would encourage them to go for amputation. So that morning I said ‘I want amputation’.”

On 1 November 2002 he had a high transfemoral amputation. The operation went well, the leg healed and he had no post-operative infections. Bob was home by Christmas and walking on a prosthetic limb.

108 miles on crutches to raise money for Macmillan

During 2003, Bob was trying to get used to his prosthetic limb and was enjoying getting active again. One day, he had the idea of raising money for Macmillan by doing the entire coastal path walk around Fife – 108 miles in all. In August 2003, he set out with his family and dog, and they were joined by groups of ramblers. Macmillan fundraisers organised press coverage and the walk succeeded in raising £16,000 for Macmillan. Bob did the entire “walk” on crutches.

After the charity walk was over, Bob was fitted with a new prosthesis and became quite agile on it. However, he began to notice a pain in his stump, which disappeared as soon as he removed the prosthesis. After further investigations, in April 2004 it became clear that the underlying cause was that the main artery to the stump had got blocked off as a late reaction to the radiotherapy, aggravated by wearing the false limb. So, in practice, from November 2003 Bob ceased wearing a limb and instead got about “even faster than before” on some good titanium crutches purchased from the USA via the internet.

Meanwhile, towards the end of 2003, around the around the time his stump was beginning to give him problems, Bob’s permanent health insurance company had suggested a review of his health. Three years had passed since he had last consulted in earnest, and this was during a period of rapid change. The upshot was that, after re-registering with the GMC, by July 2004 Bob was ready to join a practice in Kirkcaldy, Fife as a salaried GP on a part-time basis.

Despite occasional problems with the stump, Bob’s general health was excellent. During 2006, he returned to hospital to try once more to use an artificial limb. With the limb he was given, he has found it possible to walk for a few hours a week.

2004-2006: Chairman of the Scottish Cancer Group – fresh opportunities to achieve improvements in Scotland

Following early retirement, Bob had given up his Lead GP role in Fife. However, his interest in influencing cancer care did not cease. During the early 2000s the concept of Managed Clinical Networks was coming in in Scotland and Bob helped set up the first one, known as SCAN. It covered the southeast of Scotland and he chaired the Primary Care Group within it.

Then, towards the end of 2004, the Scottish Cancer Group, which had been in existence since about 2001, was going through some changes. It had previously been chaired by Anna Gregor, the Scottish “Cancer Czar”, someone, in Bob’s words, with a “clear view on where cancer services should be going”:

“Around that time there was agreement to re-jig the Scottish Cancer Group, and the Chairman’s position was advertised internally through the three Scottish Cancer Networks.”

In February 2005, Bob was interviewed and selected for the position of Chairman of the Group. His first year as Chairman was “a really good year”. He learned to understand the system and work with the Scottish Executive. Bob particularly emphasises the collaboration with patient representatives:

“We’ve now got patient representatives in the Group and one of our key aims is to make sure they can participate fully. I meet them one hour before every meeting and we go through the agenda, with me providing them with indepth background they would otherwise be unaware of. I also stay at home the day before with my phone line open, so anyone can phone me to discuss any background or politics behind an item.”

As well as chairing the meetings, in his first year Bob visited each of the five Cancer Centres in Scotland. There was a lot to learn about them, as the last few years have been a period of investment in hardware and staff:

“It’s very good to see improvements coming through. Several job vacancies that were previously hard to fill have now been filled, and we are tackling waiting times and improving patient care.”

At the end of 2005, Bob also joined the NCRI Clinical Studies Development group looking at cancer in teenagers and young adults. The aim is to organise research and to look at what’s been done, where there are gaps, and to co-ordinate clinical trials. Given Bob’s personal experience as an adolescent, this objective is clearly one that feels worth pursuing.

Support from all sides

Bob emphasises the generous support given to him during his period of chronic illness from 1988 onwards by his partners and other staff members in the practice in Markinch, Fife:

“Drs Stewart, Wallace – and later (in the final 2-3 years prior to my early retirement in 2002) Dr Lawrence – all gave me immense support and inevitably had to accept extra work during my absences. To have had unsupportive partners would have made life during those times much more difficult.”

He also comments on how supportive his family have been, including his wife Joan, his three daughters and his brother and sister: “They have all been superstars”, says Bob.

Finally, Macmillan has also played its part:

“Macmillan has been absolutely crucial in Scotland in the whole development of the Lead Cancer role and in keeping the GPs together. The support I have received – from the Scottish end and also the London office – has been incredible. Whichever way I turned there was support – financial and moral, as well as the fundraising support for the coastal walk.”

Bob comments particularly that the OSNI meetings, which brought the Scottish Macmillan GPs together once or twice a year, were very valuable for sharing ideas.

While Chair of the Scottish Cancer Group, Bob feels he should stand back a bit and be seen as unattached to any particular organisation. He is therefore maintaining links with Macmillan while focusing mainly on the Scottish Cancer Group.

Concluding reflection – motivated by personal experience

Asked how his personal experience of cancer and cancer treatment has influenced his work, Bob Grant explains that it has been the “little things” he experienced in hospital – the instances of less-than-excellent care – that particularly influenced him. But good experiences were also a major factor – for example, one doctor in Aberdeen was not only extremely good at caring but also kept in touch with Bob after he left that hospital. As a result, Bob thinks he pays more attention to his own patient care than he otherwise might have done – for example, asking patients “Now before you go, is there anything else I can help you with today?” at the end of each consultation.

As well as wanting to give best care to patients in his own practice, Bob’s personal experiences have motivated him, as we have seen, to influence health care more widely through the series of leadership roles he has taken up over the years, including Lead GP on the Lead Cancer Team in Fife, member of the Macmillan GP community in the UK, and subsequently member of the NCRI group looking at cancer in young adults and Chair of the Scottish Cancer Group.