

Lynn Faulds Wood: tell it like it is

→ Marc Beishon

Doctors don't know best if they haven't been trained. Embarrassment isn't the reason why colon cancer is picked up late. People will watch TV programmes that talk sense about cancer. Journalist and cancer survivor Lynn Faulds Wood knows how to get to the bottom of a problem and tell the world what she has found. Luckily for Europe's cancer patients, she's unstoppable.

IF there was one person who was likely to make a big impact on the cancer patient advocacy movement it would be Lynn Faulds Wood, a consumer affairs journalist and TV presenter known as 'Action Woman' from her earlier years as a magazine writer. Now president of the European Cancer Patient Coalition (ECPC), and head of her own charity – Lynn's Bowel Cancer Campaign – Faulds Wood has built up a formidable presence among the movers and shakers in the cancer world since she suffered herself from colon cancer in the 1990s.

From getting royalty – Prince Charles in this case – to say 'bottoms and bowels' on prime-time television, to lobbying the highest authorities in Europe on re-instituting a concerted attack on cancer, Faulds Wood is helping to marshal a patient movement that won't be ignored by the politicians and medical community. "Our slogan is 'nothing about us without us'," she says of her work with the ECPC. "Our aim is to get cancer back on the European agenda after the health budget cuts."

The ECPC is among several health bodies that have been highly critical of the European Commission's latest public health programme, which they say has a 'drastically' reduced budget and has removed a commitment to reduce the incidence of major diseases, including cancer. Faulds Wood and colleagues are concerned that existing work such as the European Cancer Network's quality assurance guidelines for cancer screening could be affected, while strategic objectives, such as helping countries upgrade their cancer registries and put in place cancer plans, could fall by the wayside.

While the European plan does aim to tackle health determinants such as smoking, Faulds Wood adds: "We think they are missing a huge trick. You won't change people's behaviour unless you touch their hearts, and cancer is the biggest single reason for touching their hearts on these subjects. We will be much more effective if we put cancer back on the agenda and do it properly."

Winning over hearts – and then the minds of decision makers – has underpinned much of



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her work in general consumer affairs and now health. She has a journalist's instinct to gather the evidence before 'going public', and has been highly effective in helping to remove the barriers to higher-quality care during the journey that cancer patients make, often putting medics on the spot in public arenas.

Faulds Wood started out as a French teacher – French and Spanish were her subjects at university. “Being a teacher was great because I consider education is what I've really done throughout my career,” she says. She then moved to a career in journalism, starting on a woman's

magazine as Action Woman, after she had had her own consumer experience trying to return some clothing her husband had bought her.

Headhunted by national newspapers, she took her consumer writing to the *Daily Mail* and then to the mass-circulation *Sun*, figuring that upmarket newspaper readers “could look after themselves”. It's a point she continues to make today, holding up the *Sun* to senior medical professionals and saying, “This is the audience you need to reach.” She adds that she also spent a year teaching English to foreign businesspeople, and this – and the experience on the *Sun* –



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drummed into her the need for simple, direct communications.

There is tremendous power in engaging newspapers such as the *Sun*, as she was to demonstrate in a campaign to close down a tawdry pet animal market in London's East End, which culminated in a march on Margaret Thatcher in Downing Street. Market forces duly gave way to public pressure.

Faulds Wood then moved to television, working on the new breakfast shows and also as a presenter of *Watchdog*, a consumer affairs show in which she became a household name. "I always tried to take on at least one big health story each year," she says. They included rubella vaccinations – "The government said you were protected for life and we proved you weren't" – and toxoplasmosis, which is caused by a parasite in undercooked meat that can harm unborn babies, but which can be detected with a simple blood test.

She also made a series filming the best doctors around Europe. "In one hospital in France I saw a crowd of doctors from various countries observing a procedure, and I asked how many had come from Britain. There were none. I thought this might be down to arrogance, but in

fact British doctors had so little funding they couldn't afford to travel. But we have also tended to be too insular in the UK."

Then in 1991, at the age of 40, her world fell in. From being a top TV presenter, and with new family life – she had a son of two – she was diagnosed after a long delay with advanced colon cancer. "I don't blame my doctors for not picking up the symptoms – it was fairly subtle rectal bleeding. I was told it was probably piles. I now know that a lot of us who are told we have piles actually have anal cushion bleeding, which is also pretty common. But after five months, I did ask to see the top GP at my doctors' practice, saying if it was piles they should be seen to. I finally got to see someone who examined me with a rigid proctoscope, which wasn't long enough to reach the cancer, and then I was sent for a barium enema."

All in all, it took nearly a year before Faulds Wood was diagnosed with cancer. "It was a classic apple-core-shaped colon cancer. I was shattered. I'd apparently had it for years, and I didn't know what my chances were. There was no Internet then. I remember going round the bookshops looking for information, but there was nothing on bowel cancer." It was not until a year after

treatment that she looked into data on survival, discovering that, for her stage III cancer, only 34% of people then lived beyond five years in the UK.

Meanwhile she was offered swift surgical removal of the cancer at St Mark's, London, being fortunate enough to be able to pay for private treatment (and trying to avoid the attention of the media). There was an option to have chemotherapy, but her surgeon decided to hold back and use it only if there was recurrence – a possibility as the cancer had started to invade her lymph nodes. “He made the decision. There was no discussion about it,” she says.

Subsequent tests revealed no spread to other organs, and five years later Faulds Wood received the all clear. She was left with a large operation scar from 50 staples running like a train-track down her front, and the immense psychological trauma of having to deal with cancer (she has since had skin cancer too). She threw herself back into TV work very quickly, but the media had found out and she received a lot of coverage. “I thought if I keep quiet about it, others may die,” she says. “People thought it was an ‘old man’s’ disease, but once I started talking about it I kept finding people who’d had it and never told anyone. I was about the only well-known person who would.”

As she gathered her thoughts about bowel cancer, she started to find out more about the huge disparities in treatment then existing in Britain. “Looking back it was like the Dark Ages, the quality of colonoscopy was often poor and some of the surgery shameful. While we had some of the best surgeons, such as Bill Heald at Basingstoke, we also had some of the worst, and the poorer ones didn’t seem to know it. They stayed in the same hospitals for a long time and didn’t know the rest of the world had moved on. The EuroCare data in 1999 finally showed we were among the worst in Europe for cancer outcomes.”

With her own experience out in the open, Faulds Wood inevitably turned her campaigning instinct to the medical world and to cancer. She fronted a TV programme called *Doctor Knows Best*. “It was about the role of the GP [general practitioner] as gatekeeper, and that they didn’t have a good enough chance of spotting cancers because they weren’t adequately trained to do so. Our system has not been the best. In France, for example, you can go straight to a specialist centre, and not through a gatekeeper who can stop you getting there.”

This programme was offered to the BBC, which turned it down, saying no one wanted to see cancer discussed during prime-time viewing. Faulds Wood took it to a strong investigative programme, *World in Action*, run by one of Britain’s commercial networks, and it got its highest audience – some 10.5 million – and prompted the government’s Chief Medical Officer to call Faulds Wood and promise action.

Then after making several other programmes under the title *Lady Killers*, on diseases such as cervical cancer affecting women, Faulds Wood got the ‘all clear’ about her own cancer and felt able to address bowel cancer head on. “In 1996 I made a programme called *Bobby Moore and Me*, which went out on the 30th anniversary of England winning the World Cup.” Bobby Moore was England’s football captain for the country’s greatest ever sporting triumph, but had died of bowel cancer in 1993 at the age of 51.

“Stephanie Moore, Bobby’s wife, gave her first interview, saying she’d been waiting to talk about it. She’d known that it was an unnecessary death. Bobby had four years of symptoms and was told it was irritable bowel syndrome. In the programme I went through each stage in the cancer journey and showed what was wrong in the UK, and it got 6.5 million viewers – a remarkable figure given it was in July, usually a

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very bad month for TV. I looked miserable on camera – and I was, because it was so upsetting.”

Afterwards, she received about 28,000 letters. “I spent months answering a catalogue of human misery. The TV company had never seen anything like it. That’s when I decided to give up most of my TV work and concentrate on bowel cancer.”

A key starting point was to follow up the symptoms research she’d begun with *Doctor Knows Best*. She met Mike Thompson, a surgeon based in Portsmouth, England, whose wife, a GP, had had bowel cancer, and who had a more than special interest in the disease. “I had been asking people: where is the evidence for saying that, for example, symptoms are probably piles? I was told there isn’t any such evidence anywhere worldwide, but ‘we all know what the symptoms are’. But Mike had been keeping a database of outpatients with bowel symptoms in Portsmouth – hand-entering the data himself – and his instinct was that, if he could crunch the data, he’d find symptoms were different from what most doctors believed. He had 5,000 patients in the database and I got him funding from a colonoscopy equipment maker to take a year off to do the work.”

The database, which 10 years later has nearly 20,000 records, has shown, says Faulds Wood, that symptoms are indeed different from what was then standard medical school teaching. “Bobby Moore had the classic symptoms for a one in six chance of colorectal cancer – that is, bleeding and persistent increased frequency of stools.” Having also set up a charity, Beating Bowel Cancer, in 1997, Faulds Wood was able to publish new symptoms advice for patients, and managed to enlist the then public health minister to launch it. By 2000, the government had officially adopted the advice, which has been distributed in patient- and GP-friendly forms.

“But this is still unsatisfactory. Half of us are still presenting with symptoms when the cancer is advanced. And it is hard for GPs to unlearn what they think they have known for many years. We need something more to help them when they are unsure about making a referral, and we are developing a software tool to this end. But of course screening is the best way to go.”

If the medical profession has much improvement to do, Faulds Wood is also very critical of the role of charities and patient organisations in helping to combat the disease. “I have found that people were not embarrassed to talk about bowel cancer, they just didn’t think about it. But some charities don’t make money out of telling you that this is a curable disease. They profit out of frightening you, to the extent that I think the subject has become more taboo now than it was. I find it appalling that charities are running campaigns such as ‘Shit Scared’, which was run with £200,000 of UK National Lottery money. I hate the slogan ‘Dying from Embarrassment’ – it wasn’t me being embarrassed, but my doctor failing to recognise my cancer. We can do much better than make people feel they’ve brought it on themselves.”

As she adds, the raw survival figures do not reflect the excellent chances for younger people like herself in making a full recovery, and there are good chances too for those whose cancers have spread to a few lymph nodes. Furthermore, symptoms such as rectal bleeding are very common – about one in five people have it in any one year, and it is common and normal in young people. “Mike Thompson has a slide of a penguin on an iceberg – if the penguin and the iceberg together represent the total number of rectal bleeders, only the penguin’s head is cancer.” Getting the messages across about symptoms in a non-scary way has been a major plank of her work.

She left Beating Bowel Cancer for a number

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of reasons, mostly too personal to go public on yet, and set up Lynn's Bowel Cancer Campaign. In general, she is not happy about the way many charities "have become fundraising machines mainly to sustain themselves", with large salaries paid to professional staff. "There is too much fundraising and not enough focus on saving the public from disease. Is it a coincidence that Britain, with the biggest charitable movement in Europe, has been among the worst for cancer outcomes?"

Public health messages, she adds, are just too important to leave to the voluntary sector, while the territorial disputes she's seen between organisations on who does what are 'ridiculous'.

Working through the patients' journey, Faulds Wood soon became involved in symptoms investigation, using her clout to voice concerns made by others about poor training and outdated techniques used in diagnosis. She set up a committee composed of the best people at doing colonoscopy and the best at teaching it, tasked with coming up with formal training courses for colonoscopists, and helped to find funds for 10 new training centres around the country. The use of rigid proctoscopes and barium enemas, the latter still in wide use in some regions in the UK, were firmly in her sights, having had them herself.

"One of the best things I did was a talk in 2002 at the Royal College of Surgeons in front of 250 of the world's leading surgeons. My feeling was, based on the Portsmouth database and talking to doctors, that we could diagnose people better in a more patient-friendly way. We should be doing flexible sigmoidoscopy, not full colonoscopy or barium enema, on people with bleeding or change of bowel habit, because cancers tend to be in reach of flexi-sig and it is cheaper and much less unpleasant. I asked them to imagine they had rectal bleeding, and using keypad voting I got them to choose what they would like themselves. Ninety percent wanted a flexi-sig. I was sitting next to the then Chief Medical Officer, and I said to him that most people in Britain couldn't get it. Patients need to have as good an experience as possible when hunting for this disease. Barium enema is a pretty unpleasant and costly experience."



Training people in flexi-sig also helps identify people with an aptitude for the more difficult colonoscopy, she adds.

Faulds Wood is now an old hand in negotiating the Byzantine world of British healthcare committees, and has become a campaigning patient representative on the key colorectal cancer meetings. "The most important committee I sit on is the National Bowel Cancer Audit project, run by the UK's Association of Coloproctology. It is looking at a number of variables for measuring hospital performance, including deprivation in the local population."

The plan is to publish performance data for colorectal cancer treatment by centre, adjusting for the worse outcomes in more deprived areas. But as Faulds Wood comments, centres will not be publicly named for three years. "It is not just a surgical disease anymore. Outcomes depend on a team approach and an anonymous period will give poorer performers a chance to catch up. It could just be an audit clerk who's not doing well, when the clinical team is really good. Audit is expensive, but patients have a right to know about the hospital they are going to, and there are some I would not go to at present." Such auditing is an area where Britain is leading in Europe, she adds.

Faulds Wood is a proponent of the concept of the 'uniquely informed patient' – patients with the skills to become role models and

Queen of PR.
The media had proved prudish about covering colorectal cancer stories, so Faulds Wood invited Prince Charles to talk about 'bottoms and bowels' on the national news



An alliance against cancer. Faulds Wood, in her capacity as president of the European Cancer Patient Coalition, with EU Health Commissioner Markos Kyprianou (right), and the co-chairs of MEPs Against Cancer, Alojz Peterle (left), Adamos Adamou (centre) and Liz Lynne, at a MAC conference, Brussels 2006, which issued a call for action to tackle the growing epidemic of cancer

advocates for others. She feels that across the board, from local voluntary work to the highest platforms, cancer patients are not being involved enough, partly because there is a view that they do not want to discuss their experience. “But you can’t shut me up about bowel cancer, and there are plenty of others like me.” Patients groups do now have a welcome presence at major oncology conferences, she adds, but they should be integrated even more into the meetings, while the fact that patient advocates are usually the only unpaid people on committees should be addressed.

In the UK she has helped set up patient parties – social gatherings of bowel cancer patients and their families, where they mix with health professionals to feed back information on hospital facilities, treatment and support. One reason for running these parties, she says, is to identify patient representatives who may like to work on committees. Active bowel cancer patients are much more scarce than those who have had breast cancer.

Patient organisations can also help find people with familial predisposition, which Faulds Wood has done on TV to find HNPCC (hereditary non-polyposis colorectal cancer) families, and to help doctors recruit people for clinical trials. “I’m doing a speech soon on patient communications. Doctors really need marketing skills to sell their trials,” she says.

“I’m also involved in a big seven-centre trial and looking at the value of follow-up. Extensive follow-up can be very expensive, and with the

world changing so fast and recruitment so slow, by the time you get people in trials they can be out of date.”

There is also a question of finding out what trials are actually being conducted. “At the moment patients can’t find out about trials. One of the most important things we are doing in ECPC is pushing for a register in lay language of clinical trials, including phase I, which the pharmaceutical industry don’t really want us to have. But it is very important that patients know from phase I what’s out there.”

And while excited about new targeted therapies and genetic research, she feels there is a major funding imbalance between the ends of the cancer ‘cycle’, with relatively little spent on prevention, screening and early diagnosis. “The only good thing about colorectal cancer is you can find it in a precancerous phase and never need any drugs.” There also needs to be more emphasis on quality of life, “leaving us as bodily intact as possible”, including preserving sexual function and the use of keyhole surgery. “We could reduce stomas from 25% to 10%,” she adds.

Faulds Wood was a cofounder of ECPC, and as the current president is heading a board of other cancer survivors developing a number of initiatives from patient advocacy masterclasses to lobbying for the trials registry, while her international schedule is starting to rival a top oncologist’s itinerary, from talks at psycho-oncology and gastroenterology conferences to being the only overseas member of the US National Colorectal Cancer Roundtable, which brings together doctors, business leaders and patient groups.

ECPC is involved in designing the bowel cancer screening guidelines for Europe, and is building a colon cancer patient group network. But in general it has become an umbrella group for all cancer groups other than breast, where Europa Donna already has a leading presence – a necessary step, says Faulds Wood, as it would be impossible for all groups to get round a table in Brussels.

Over 200 member organisations are now in ECPC (and new ones are always welcome via www.ecpc-online.org, she adds), and the

masterclasses it runs are gearing up to unleash a formidable force of Euro-savvy patient advocates around Europe. “ECPC also runs the secretariat for MEPs Against Cancer (MAC, launched in March 2006). Alojz Peterle, the former Slovenian prime minister, is co-chair of MAC and also chairs the largest political group in the European Parliament. The next ECPC summit for accession countries will be in Slovenia in November, with high ranking officials invited, and leads into Slovenia having the 6-month European presidency where for the first time the focus is going to be cancer. We are really having an effect.”

Lynn’s Bowel Cancer Campaign (www.bowelcancer.tv) is currently run from her London house and has a mix of regular and one-off events. “We put the emphasis on raising awareness rather than just saying, ‘Give us all your money,’” she says, mentioning 25 motor-bikers wearing ‘huge pants’ (message: ‘say pants to bowel cancer’), who cycled the length of Britain for the campaign. It was another clothing item – ‘the loud tie’ – that got Prince Charles involved. “We had a 17-storey-high, bright-red tie, handpainted by cancer patients, dropped from a building on the day. A friend who worked in TV called me and said, ‘Did you know you got £30 million worth of news coverage?’” She even helped the last Pope – who had bowel cancer – to launch a global awareness campaign.

She doesn’t think that as a ‘TV personality’ she has any great advantage. “Other charities use expensive PR people, and could do equally well,” she says. There has also been some criticism of the role of celebrities in urging people to go for screening procedures that could be harmful and unnecessary. Faulds Wood agrees, noting she has never advocated that younger people without symptoms have colonoscopies, and her commitment to developing evidence-based screening protocols and good information about symptoms



Facts first. This leaflet tells you which symptoms you need to worry about, and which you do not. Until Lynn’s Bowel Cancer Campaign funded the research on which this leaflet was based, neither doctors nor the general public had evidence-based information to go on

– and not propagating fear – is clear. She is very pleased though that England is now among the first countries with a national colorectal screening programme for those aged over 60.

Home life for Faulds Wood revolves around husband John Stapleton – also a well-known TV presenter – and son Nick, who plays in a rock band called Damn Sly (“First I was his roadie, now I’m a groupie,” she says). Long walks – a health-promoting exercise that should be advocated more often, she adds – are a staple pastime.

Cancer work looks set to dominate her life for the foreseeable future, at least until what she terms the ‘patient-friendly’ agenda is firmly established around Europe. “I’ll know we’ve achieved something when we all stop talking about partnership with patients and are actually doing it,” she says.

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