Cancerworld
Education & knowledge through people & facts

Number 15, November-December 2006

Lynn Faulds Wood

→ Lynn Faulds Wood: tell it like it is → The write stuff: helping health journalists do a better job → Breast cancer stamp raises $50 million... and some sticky questions → Minimum volumes: are vested interests taking precedence over patient care?

Editor
Kathy Redmond
editor@esoncology.org

Assistant Editor
Anna Wagstaff

Editorial Assistant
Mariarita Cassese

Contributing Writers
Marc Beishon, Riazat Butt,
Simon Crompton, Catherine Kalamis,
David Kerr, Emma Mason,
Peter McIntyre, Carolyn Runowicz,
Anna Wagstaff

Publishing Advisors
Gillian Griffith, Fedele Gubitosi

Website Liaison
Chatrina Melcher

Project Designer
Andrea Mattone

Graphic and Layout Designers
Pier Paolo Puxeddu+Francesca Vitale

Production Manager
Gianfranco Bangone

Published by
Editoriale Darwin srl
Piazza Antonio Mancini, 4 - 00196 Rome

Printed by
Miligraf snc - Roma

Cover photograph
Eligio Paoni / Contrasto

Registrazione Tribunale di Roma
Decreto n. 436 del 8.11.2004

Direttore responsabile
Emanuele Bevilacqua

All enquiries about *Cancer World*
should be made to:
ESO Editorial Office
Via del Bollo 4
20123 Milan, Italy
e-mail: magazine@esoncology.org
Fax: +39 02 8546 4545

All correspondence should be sent
to the Editor at editor@esoncology.org

Contents

European School of Oncology
Learning to care

Cancer World is published six times per year by the European School of Oncology with an average print run of 10,000 copies. It is distributed at major conferences, mailed to subscribers and to European opinion leaders, and is available on-line at www.cancerworld.org

The write stuff

➔ Kathy Redmond ■ EDITOR

Cancer has a pretty poor public image. Myths and misconceptions fuel negative attitudes and ignorance about the disease. The media, in turn, can either fuel these misconceptions, or it can challenge them.

Good journalism helps people understand that cancer affects everyone, and that the experience of cancer patients and their chances of surviving with a good quality of life depend heavily on cancer services getting it right, from early detection to rehabilitation and long-term support.

Bad journalism portrays cancer as a virtual death sentence on the one hand, while spreading the false hope of 'wonder drugs' on the other. Talk of 'brave' or 'tragic heroes' denies readers an understanding of the reality of living with a cancer diagnosis while failing to ask pressing questions about what is needed to improve the experience of patients and their families. As a result the general public remains ignorant about cancer, negative attitudes are reinforced and health services are let off the hook.

This issue of *CancerWorld* showcases examples of where journalists and the media have made a positive difference. The stories demonstrate how effective the media can be in challenging the public's sense of powerlessness in the face of cancer, by raising awareness about how we can bridge gaps and address inequities in access to care, and by conveying important messages: that the quality of cancer care can vary widely, that early diagnosis saves lives, and that life does not stop because you have cancer.

Cancer can be a challenging topic to cover well. Journalists often face problems in accessing clear, up-to-date, accurate information, finding credible sources and resisting the pressure to sensationalise stories to make better headlines. We can help them do a better job by providing the information they need and clarifying the science behind the story. We should acknowledge journalists when they are doing a good job. The European School of Oncology's Best Reporter Award provides one example of how this can be done.

It is probably impossible to get rid of sensationalist media reporting of cancer altogether. However, we should not sit back and accept poor journalism as inevitable. We need to work with the media, to promote critical and intelligent coverage that will improve the public's understanding of what cancer is and what can be done about it.

All correspondence should be sent to the Editor at editor@esoncology.org

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


ELIGIO PAONI / CONTRASTO

She is helping to marshal a patient movement that won't be ignored by politicians or the medical world

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 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* –

ELIGIO PAONI / CONTRASTO

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

The BBC turned it down, saying no one wanted to see cancer discussed during prime-time viewing 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

"It wasn't me being embarrassed, but my doctor failing to recognise my cancer" 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.

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

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

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 motorbikers 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 – 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.

BOWEL CANCER SYMPTOMS?

Do you know the main symptoms?
Try the traffic light test to find out what to do:

RED: Highest risk symptoms:
- Recent change of bowel habit to looser, going more frequently with rectal bleeding lasting over 4 weeks
- Lump in tummy felt by doctor
- Unexplained anaemia
- Persistent bleeding without reason over 55

STOP: See your GP soon - you should be referred to hospital for investigation at any age but 5 out of 6 people will NOT have cancer.

AMBER: Higher risk symptoms which might need investigating:
- Recent change of bowel habit with no bleeding
- Bleeding without any reason under 55

WATCH & WAIT: Take up to six weeks to test your symptoms - it's safe.
Change your diet, talk to a pharmacist - if symptoms persist go to your GP.

GREEN: A wide range of bowel symptoms which come and go without getting worse:
- Bleeding with itching, soreness, lumps and bumps
- Change of habit to going less frequently
- Harder stools or changed shape
- Mild tummy pain which doesn't affect your life
- Bloating

GO on with your life reassured you do not have cancer symptoms but if they worry you or last for more than two months, see your GP.

Lynn's Bowel Cancer Campaign
5 St George's Road Twickenham TW1 1QS
www.bowelcancer.tv

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

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.

> There needs to be more emphasis on quality of life, "leaving us as bodily intact as possible"

Turn up the volume

Anna Wagstaff

If you had cancer, you'd want to be treated by experienced specialists working within a specialised multidisciplinary team. So why are so many of Europe's cancer patients still being treated in hospitals whose case-loads are clearly too low to provide this level of care?

Periodically articles appear in cancer journals revisiting the growing evidence on the link between volume and outcomes, and contemplating what action, if any, should be taken in response.

Judging by the weight alone, the evidence that patients have worse outcomes if they are treated by physicians or at hospitals with a lower case-load of similar patients is pretty conclusive.

An overview published in 2002 of a total of 135 studies (*Ann Intern Med* 137:511–520) revealed that 71% of studies of hospital volume and 69% of studies of physician volume reported statistically significant associations between higher volumes and better outcomes. This included 10 out of 12 studies on pancreatic cancer surgery (showing a median difference of 13 deaths per 100 cases), three out of three for oesophageal cancer surgery (12 deaths per 100), two out of two on breast cancer surgery, eight out of 15 on colorectal cancer surgery, two out of five in lung cancer and three out of five in gastric cancer (see Table).

In studies that found no significant difference in outcome, the results indicated either a relationship that fell short of significance or no relationship at all. There is almost no evidence of any inverse relationship between volume and outcome.

This is all quite compelling stuff. So why is it that thousands of cancer doctors treating small numbers of patients in small hospitals all over Europe do not feel compelled to stop?

There is now a general acceptance that when it comes to "tricky procedures", such as pancreatic and oesophageal surgeries, it is the skill of the surgeon, and indeed the intensive care unit, that counts most, and this is likely to be lower in surgeons/ITU departments that handle few cases a year.

However, variations in outcomes for other cancers may not be so tightly related to volume – indeed the review of the studies showed that they are not. For every study that shows a volume–outcome relationship for gastric cancer, or ovarian or breast cancer, there are two that indicate that the main cause of variations can be explained by factors other than volume. Some point to failings in the pathology, mistakes in the diagnostic work-up, or incorrect staging leading to over- or undertreatment. Others point to the absence of a multidisciplinary discussion, poor selection of treatment modality, usually an under-referral to chemo- hormonal or radiotherapy. Lack of specialist training and/or failure to follow guidelines are also frequently mentioned factors.

OVERVIEW OF THE LINK BETWEEN HOSPITAL / PHYSICIAN VOLUME AND OUTCOME

Type of cancer surgery	Studies included	Studies with a significant volume–outcome association	Median cases a year defining low volume (range)	Median cases a year defining high volume (range)	Median average mortality rate (range)	Median absolute difference in mortality rate for high vs low volume
Pancreatic	**10**	**9**	**5 (1–22)**	**20 (3–200)**	**9.7 (5.8–12.9)**	**13.0 (3.0–17.9)**
	2	1	1 and 9	10 and 42	8.0 and 12.9	7.0 and 10.2
Oesophageal	**3**	**3**	**5 (5–10)**	**30 (11–200)**	**13.9 (8.9–14.0)**	**12.0 (11.0–13.9)**
Breast	**1**	**1**	**10**	**151**	**N/A**	**a**
	1	1	10	50	N/A	N/A[b]
Colorectal	**10**	**4**	**18 (10–84)**	**115 (18–253)**	**6.0 (3.5–12.3)**	**1.9 (-1.2–9.7)**
	5	4	12 (5–21)	22 (9–40)	3.0 (2.0–6.0)	1.0 (1.4–1.9)
Lung cancer	**4**	**2**	**7 (5–37)**	**19 (11–170)**	**5.5. (1.9–12.9**	**1.9 (1.6–3.9)**
	1	0	22	132	1.9	1.1[c]
Gastric	**3**	**1**	**10 (5–15)**	**63 (15–201)**	**10.9 (6.2–12.2)**	**6.5 (4.0–7.1)**
	2	2	1 and 2	2 and 12	6.2 and 12.2	4.0 and 5.7

a **Outcome data were for 5-year survival, not short-term mortality. Patients receiving care at the lowest-volume hospitals had a 60% higher risk for death within 5 years than those undergoing surgery at high-volume hospitals.**

b Patients with high-volume surgeons had better 5-year survival (odds ratio: 0.85)

c Difference in mortality rates between high- and low-volume surgeons was of borderline statistical significance (P=0.08)

Source: Ann Intern Med 137:511-520

There are three reasons to question over-reliance on the volume=quality assumption. Firstly, the correlation between volume and outcome, though real, is an inconsistent and unreliable reflexion of the multiple underlying factors that really make the difference. It would therefore seem sensible for strategies for improving outcomes to concentrate on these underlying factors rather than on volume.

Secondly, concentrating on volume can have undesired side-effects – pressure to keep up personal volumes could, for instance, influence a surgeon's decision on what treatment to recommend for lower-risk prostate cancer patients.

Thirdly, adopting volume as a quality criterion would force many doctors, departments and hospitals to stop carrying out certain cancer procedures. This will mean some cancer patients will have to travel further for their treatment. For some patients, and some one-off procedures, this may not be a problem. For patients who are frail, very unwell, or find it difficult to travel, it can turn an already bad experience into a nightmare. Why do this to patients if the outcome benefit seen in larger hospitals can be replicated in smaller centres by replicating the multidisciplinary structures, the diagnostic procedures, the level of specialisation, the protocols or whatever is responsible for the better outcomes?

There is another reason why many cancer patients are still treated in centres that don't see a large number of similar patients in a year – straightforward self-interest on behalf of the doctor and/or the centre. Many doctors in Europe are paid per patient or per procedure, and removing their right to treat cancer patients who come their way would hit their income. There is also a certain status involved in treating cancer, and doctors may resent the blow to their prestige, or worry that giving up cancer cases will affect their career prospects. For many the main deterrent to giving up treating cancer patients is simply job satisfaction.

Similar mechanisms work at an institutional level. Hospitals are less likely to refer patients to a specialist centre if they lose money as a result. There is also a fear within some local general hospitals that if they concede the principle with respect to one type of cancer or indication, then bit by bit they will lose more patients to specialist centres and ultimately become unviable, and the hospital will be closed.

Pressure from self-interest can, however, also work in the opposite direction, where large hospitals and specialist centres may be looking to expand in size and prestige.

“Taken together, the evidence paints a consistent picture that must be taken into account”

Mounting pressure

In May 2003 an editorial appeared in the *Journal of the National Cancer Institute,* entitled *Taking action on the volume–quality relationship: How long can we hide our heads in the colostomy bag?* The title referred to the latest addition to the evidence on volume–outcome, published in the same issue. It showed that out of every hundred patients treated for colorectal cancer, seven more deaths would be expected if the patient was treated at a hospital dealing with less than seven cases a year than if they were treated at a hospital dealing with more than 20. Patients would also be 7% more likely to undergo a full colostomy at the smaller centres.

While accepting the need to dig deeper into the factors behind the discrepant outcomes, and agreeing that “the better long-term solution would be to disseminate the components of practice that lead to better outcomes,” the editorial injected a sense of urgency into the debate, suggesting the time had come to talk in terms of minimum volumes, where a hospital whose admission rate was below the minimum would have to refer patients to a larger centre. The authors pointed a finger at vested interests in the medical profession. “Colostomy rates or mortality rates that are unexplainably high for similar patients are simply not acceptable. If these decisions did not involve livelihood, prestige and power, we would have demanded action long ago.”

Three years later, however, the same journal seemed to put the brakes on again. An editorial titled *Transcending the volume–outcome relationship in cancer care*, which accompanied newly published findings on the volume–outcome relationship in ovarian cancer, warned against reading too much into published relationships between volume and outcome.

Reporting on the studies, it said: “higher hospital volume was associated with lower two-year mortality, with or without case-mix adjustment – but the relationship lost statistical significance (by conventional standards) once surgeon volume was entered into the equation” and “a modest positive association between hospital volume and overall survival remained after case-mix adjustment, but the association was no longer statistically significant once surgeon volume was included and weakened even more after accounting for whether the patient had postoperative chemotherapy.” It then went on to make a case for something that the study in question had not been designed to explore and was therefore unable to draw conclusions about: “key elements of ovarian cancer treatment generally considered to be quality enhancing and that may be associated with better survival… generally delivered superior care.” The take home message was: more research looking at more cancers in more detail is needed before we take any action.

The principle behind trying to identify the specific mix of structures, processes and volumes that can account for statistical differences in various outcome measures is surely a good one. But there is a danger of being sucked into a level of detail where it is hard to draw any meaningful conclusions. Worse still, it becomes very easy for anyone with their own agenda to pick and choose the evidence to suit their argument, which risks bringing the integrity of the whole debate into question. The resulting confusion and scepticism serve only to reinforce inertia to making changes to a status quo that is known to be letting many patients down.

Common sense

Bob Haward, recently retired professor of cancer studies at St James University Hospital in Leeds, UK, got to know this area of literature very well when, at the end of the 1990s, he was given the task of helping improve the UK’s poor survival rates through drawing up guidance for treatment of the major cancers. He advocates the use of common sense.

He points out that whether the conclusion regarding management of a particular cancer is that what matters most is volume (be it surgeon or hospital), or a correct choice of treatment modality (implying a multidisciplinary approach), or level of specialisation, or correct diagnostic procedures, the practical implications all point in the same direction. Against very low case loads.

“There is a simple logistics thing. If you are setting up a sarcoma team with people who are knowledgeable and experienced, you can’t do this for


JON NICHOLSON / CORBIS

Looking ahead. The evidence and common sense indicate that patients' chances of surviving with a good quality of life are likely to be higher if they are treated by teams who specialise in that sort of work

a population of 100,000, because the team would be meeting about once or twice a year. A breast team can function with a population of 100,000. A sarcoma team can't."

A similar argument applies with specialisation. "If you go back to the original work done in the West of Scotland, for instance, they found that the specialist gynaecologist got better results than the general gynaecologist, who got better results than the general surgeon operating on ovarian cancer. That gradation from generalist to specialist is a reasonably consistent theme in a modest number of papers in the literature. So that suggests there may be something going on. But of course if you are a specialist in something you are likely to be doing a lot more of it, so that overlaps substantially with this whole question about volume and outcome."

As for the evidence that volume has an independent effect on outcome, Haward believes it is robust, and applies far more widely than pancreatectomy and oesophagectomy – in particular when you go beyond the usual outcome measures of post-operative complications or survival, to look at the quality of life these patients are left with.

The evidence cited in the JNCI editorial that colorectal patients are 7% more likely to be given a full colostomy if they are treated in a smaller hospital is echoed by figures for full mastectomy in breast cancer. Experience counts when it comes to getting accurate results from a sentinel node biopsy, avoiding damage to the axillary nerve, and even minimising the cosmetic damage where full mastectomies are warranted. For patients, this translates into lowering the risk of lymphoedema, preserving good arm and hand function and better body image. The story is similar for gynaecological and prostate cancers, in terms of protecting patients' sexual function, continence and fertility.

Volume can also be important when it comes to certain diagnostic procedures: in addition to the sentinel node biopsy, the quality of mammography, and endoscopic colopancreatography have been shown to improve with frequent practice.

Finally, practice and experience can also breed confidence. There is now evidence from a range of cancers – testicular, gastric, and germ cell – to indicate that patients do better with doctors who do a lot of that particular type of treatment, because when complications arise, they are less likely to be blown off course and deviate from the protocol.

Haward freely admits that none of the evidence, taken alone, is of the quality physicians expect when drawing up guidelines. But taken together, he argues, it paints a consistent picture that must be taken into account when considering how to structure the delivery of cancer services – even if some doctors or hospitals lose out as a result.

"People feel there is a rough justice in using this [minimum volumes] to determine policy. There is a feeling that if only you could work hard enough and disentangle what it is about high volume that gives the good outcomes, we could all do it in our low-volume centres and get as good outcomes as they do. I don't think this washes.

"I agree there is a rough justice aspect to it, and there probably are some clinicians in small centres who

TOO FEW

- Good quality cancer care requires specialist pathologists and radiologists to give a detailed and accurate diagnosis, a specialised multidisciplinary team to decide on the best treatment plan for each patient, and specialists, with strong back-up, to carry out complex or tricky parts of the treatment.
- Smaller hospitals are unlikely to have enough patients to merit employing specialists in every cancer, or to merit regular multidisciplinary team meetings. Doctors treating low numbers of patients can not develop the skills and expertise of their colleagues treating high numbers of patients every day in specialist centres.
- Patients pay the price with a lower chance of survival and a higher chance of having their lives blighted unnecessarily by loss of bowel function, loss of a breast, loss of their sex life or their fertility.

get as good results as their colleagues in the bigger centres, and there are some poor services in bigger centres. But in general I think we ought to be taking this literature seriously, and try to organise services in such a way that we provide the configuration of service that is most likely to lead to the best outcomes. Certainly we should be eliminating the thing that most people would agree is unsatisfactory, which is very low volume complex-procedure work."

And that is exactly what happened as the UK was divided into 34 cancer networks, where each was asked to ensure that all patients were treated by multidisciplinary teams with expertise in the relevant cancer and with a minimum expected case load, according to the population it served. For colorectal cancers this was specified as a minimum population of 200,000, for oesophago-gastric cancer teams and rare head and neck cancers, such as thyroid cancer, as a minimum population of one million, and for pancreatic cancer teams, two to four million.

Inevitably, the policy created resentment among some of those who lost their right to treat cancer patients. That's life, says Haward. "No doctor has the divine right to practice medicine any way he or she sees fit." The health service, he says, isn't there to look after doctors' needs, they are in the health service to look after patients.

He does feel, however, that posing the issue of minimum volumes as a stark choice between whether or not to centralise specific cancer services may have been unhelpful and could have contributed towards polarising the debate.

STRIKING A BALANCE

Haward points out that even where an element of care needs to be centralised, that does not mean that the totality of care needs to be centralised. He says that one of the most satisfying aspects of the UK policy development was the widespread recognition that cancer care is multidisciplinary at the level of deciding clinical management and organising who does what, and how. "We've tried to strike a balance between different institutions and the personnel in the community and local hospitals as well as more specialist hospitals. We have tried to encourage the idea that good cancer care is a partnership between community and local hospitals and more specialist and more remote services. It is not all or nothing."

In practice, he says, the system has shown it can take advantage of opportunities to keep treatments local. One such opportunity arose when the number of non-surgical oncologists in district general hospitals more than doubled as part of the cancer plan. "In ovarian cancer you probably do need to centralise the decision about what is the most appropriate form of chemotherapy, but very often you don't have to centralise its delivery. And networks have taken the spirit of Calman-Hine [the report behind the UK reorganisation], namely that the specialist team needs to think about what management the patient should get, but many are now quite satisfied that platinum-based chemo can be safely delivered by many of the district general hospitals, so there is no need for patients to come all the way to the larger hospitals to get it." Efforts are also made to keep palliative care as close to home as possible while still offering a specialist multidisciplinary service.

One way this local care delivery has been achieved is through videoconferencing, which allows, for example, palliative care specialists or medical oncologists delivering chemo at district hospitals to take part in multidisciplinary meetings involving regionally based specialist teams.

If cancer continues to become more like other chronic diseases over the next 10–20 years, Haward says that the current network structure could easily adapt further to include, for instance, community-based cancer clinics run along the same lines as diabetes clinics, and a far greater level of patient self-management.

Some voices still urge caution

until further research has been conducted, but there are indications that they may be running out of time. In the US, the Leapfrog Group, a coalition of around 140 public and private purchasers of health care, has adopted minimum volume quality criteria for pancreatic resections (11 or more per year) and oesophagectomies (13 or more), and is keeping other cancer treatments under review. Many European health insurers are beginning to look at following suit – surgical complications, tumour recurrence and metastatic disease all cost extra to treat, so the payer shares the interest of the patient in getting it right first time.

In Switzerland, where the 26 cantons have for centuries guarded their independence fiercely, attempts are being made to rationalise cancer service delivery across the country. Defining minimum volumes where appropriate is one principle. "The federal office of public health has given a mandate to different people to define [minimum volumes] and to try to get the figures incorporated into the insurance process," says Reto Obrist, a medical oncologist from the Vallais canton, and a key player in the development of the Swiss national programme against cancer. "One could imagine that in a couple of years, insurers will only pay if such and such intervention is done in a hospital with a minimum volume."

Insurance companies are already flexing their muscles, insisting, for instance, that patients participating in trials using peripheral stem cell transplantation for lung cancer would be reimbursed only if they were treated at a particular centre in Lausanne. Obrist expects similar restrictions to be placed on pancreatic resections and, possibly, oesophagectomies. But he is painfully aware that the problem goes deeper than that. Despite recent progress towards concentrating gynaecological cancer services in specialist hospitals, for instance, Obrist admits that in his own canton, on average every gynaecological surgeon operates around three ovarian cancer patients a year, "which is awful, but I have no means to change that".

He says that there is a certain envy of the French, "because they can implement things in a top-down manner. We are not in that situation, so we have to work from the periphery up."

There are hospitals that are deciding of their own accord to stop doing procedures they feel they have insufficient expertise in, and in Switzerland this trend may speed up considerably if insurers decide not to pay separately for the costs of treating any complications that may arise. Others are calling in experts from regional specialist centres to take on tricky operations. Some are even paying surgeons with low volumes not to operate.

Patients are also increasingly taking matters into their own hands by choosing to travel sometimes long distances to be treated in hospitals that can show they have a high case load and good results. It is an option that may work well for them, but there will be many more patients who are less assertive or less able to travel who remain behind in hospitals with ever-dwindling case-loads.

Pressure to stop doctors treating low volumes of cancer patients is now building from some of the professional bodies. In 2000 the European Society of Mastology became the first Europe-wide professional oncology body to issue guidelines over minimum case loads. Their recommendations for specialist breast units included a mandatory requirement that the unit as a whole "must be of sufficient size to have more than 150 newly diagnosed cases of primary breast cancer," and that individual breast surgeons "must personally carry out the primary surgery on at least 50 newly diagnosed cancers per annum."

The guidelines have been welcomed by many breast cancer patient groups, including Europa Donna, and have been referred to in a European Parliament resolution. The response from Europe's medical community, however, has been more muted. In Switzerland, says Obrist, the guidelines have not gone down very well in the profession. Karin

TOO FAR

- Concentrating certain cancer services in specialist centres that treat a minimum number of patients or cover a minimum catchment population means some patients will have to travel further.
- For patients who are less used to being far from home, have poor access to transport, have no friends or family to help them, and have an arduous route to travel – possibly daily for weeks at a time – travelling to a specialist centre can be an ordeal, particularly if they are already feeling very unwell.
- Ideally cancer services should be organised to allow patients to receive each element of their care package as close to home as possible without compromising quality. Transport facilities and ease of access have to be considered when choosing which hospitals to designate as specialist centres.

“Specialists in colorectal or ovarian cancers travel to assist with operations in the smaller hospitals”

Jöns, a breast cancer survivor and MEP, has complained that in Germany hospitals are banding together to give the appearance of fulfilling the criteria without actually changing the way they work.

In the Netherlands, however, the national scientific committee on breast cancer is proposing that EUSOMA’s criteria be adopted as national guidelines. Furthermore, the country’s larger cancer centres are arguing for all cancer work to be concentrated in no more than 20 hospitals across the country. This would be a major change, for instance, for the breast cancer patients living in the area covered by the North Netherlands Comprehensive Cancer Care Network – one of nine such networks – who currently have 16 hospitals to choose from in their region alone.

Renée Otter, director of the North Netherlands network, fully accepts the need to refer patients needing tricky procedures, particularly for less common cancers, to specialist centres. However, she is convinced that the proposed level of centralisation for breast cancer surgery cannot be justified, and that the net effect would be to deliver a worse service for patients because they would be forced to travel so far from home, for little benefit.

She and her colleagues decided to examine the evidence from their own region, where hospitals have for years been recording detailed data on case management. They wanted to find out whether differences in outcome could be attributed principally to the surgeon or to the ‘oncology management and policy’ at the hospital, and what influence volume had on either. The outcome measure they used was the proportion of early breast cancer patients treated with breast conserving therapy (controlling for case mix).

Instead of the usual regression analysis, this study, accepted for publication in *Breast Cancer Research and Treatment*, used a method adapted from industry to look at the relative importance of differences at the level of the patient, the surgeon and the hospital. Differences between surgeons accounted for just over 5% of differences in outcome, but exactly what made one surgeon better than another was not clear. Membership of the regional tumour working group had the strongest effect; volume, defined as greater or less than 30 patients a year, did not seem to play a significant role. At the level of the hospital, which accounted for almost 3.5% of outcome differences, volume (using a threshold of 100 patients) did play a role, but the effect did not reach statistical significance. What did stand out was the importance of multidisciplinary care – especially the cancer conference and the composition of the multidisciplinary team.

Otter argues that EUSOMA itself is “more focused on the cooperative specialist multidisciplinary team – on processes and structure – than on volume alone,” and feels that the North Netherlands study shows a slightly lower level of centralisation may be safe, so long as these other criteria can be fulfilled. But like Haward, she recognises that the two issues are inextricably linked, and the study concludes that “hospital volume is not the final factor, but a minimum volume is a prerequisite for well-organised care, e.g. multidisciplinary teams and conferences.”

She believes that if insurance companies are going to set quality indicators, in the case of breast cancer the requirement should focus on treatment via a specialist multidisciplinary team that meets for some hours at least once a week. “If you are not able to arrange this, because it will take too much time from other work, this means that you do not have enough patients and you should stop treating this kind of patient.”

The North Netherlands network has started looking at how groups of smaller hospitals can collaborate to provide specialised multidisciplinary cancer services for patients drawn from a combined catchment population. Surgeons specialising in colorectal or ovarian cancers travel to assist with operations in the smaller hospitals. Heavy use is made of videoconferencing to ensure the participation of specialist pathologists, radiotherapists and all other members of the team in multidisciplinary conferences.

The aim, says Otter, is to ensure that around 70% of cancer patients can be treated locally, with the remaining 30% of rare or difficult cancers being referred to specialist centres. Time will tell whether the hospitals will be able to achieve the required level of collaboration. “If they are not willing to start with such communication techniques, I will not push them any more, and all patients should be referred."

Otter believes that local treatment is worth fighting for. She talks of the time breast cancer screening was rolled out across the Netherlands. "In some areas, where it is agricultural, the women came very late to the doctor and they all had T4 breast cancer. It was ulcerating. These kinds of people have to work hard for their income, and they go on till they fall down. If they come to the hospital usually it is too late. But even when they come, if they are told they have to go 200 km from their home, I wonder whether they will do it. Not all of them will."

Such research as has been done among patients in the North Netherlands region has shown a range of attitudes. "If I remember rightly a quarter of them said it doesn't matter how far, but I'll go. Others said, it depends for which kind of things I have to go elsewhere, and why I couldn't get it here."

Haward believes that doctors sometimes overemphasise the importance patients attach to local treatment to suit their own purposes. But he agrees that if you are going to stop smaller hospitals carrying out certain procedures, it is important to explain why.

He tells the story of what happened when, shortly after the publication of the Calman-Hine report into the reorganisation of the cancer services, a proposal was made to close some of the gynaecological cancer services in a hospital in a town on the south coast. "The local people wanted to keep the service, but the supporters of Calman-Hine were arguing that certain patients should be sent to a specialist centre further away." The health authority put the question to the public. It organised a 'citizens jury' made up of a representative group of local people, including patients, and invited them to listen to the evidence, and hear witnesses from both sides. "What was interesting was that when the citizens jury actually had the arguments laid out, they had no problem with certain types of patient needing to travel the extra distance."

Not all patients have the same priorities. And what may be acceptable to fitter, younger patients may be traumatic for elderly or very sick patients. Cultural factors also play a role. Otter accepts that she might think differently if she were in the States, but patients in the Netherlands, she says, are used to having good care close to home.

Haward has noted a 'paradox' at international meetings. "The countries that were most concerned about the whole business of local versus more centralised services were the smaller countries where even centralised services weren't very far away for patients. It was Israel, Holland and the UK that were really bothered. Countries like Canada, Sweden and Australia weren't in the least bit bothered."

It is an interesting observation, and points to the potential for attitudes to change, but it also points to the need for health systems to find ways to take account of the priorities of the patients they serve. Otter says that in the Netherlands, pressure from patients associations has "opened the eyes of the professionals to discuss better what they can and what they can't deliver locally."

Asking patients about their preferences and priorities regarding the way their cancer services are delivered is important. But in many countries, the whole issue of how best to organise quality cancer services is not being systematically addressed by anyone, be they patient, professional or policy maker. There is therefore a simpler question that health service managers, administrators and policy makers needs to ask, and it this: *Would you like us to look into the options and discuss them with you?"*

There would be no need for a citizens' jury to find the answer to that question. And to echo the editorial that appeared in the JNCI more than three years ago: If this question did not involve livelihoods, prestige and power, policy makers all over Europe would have asked it years ago.

TURNING UP THE VOLUME

Countries with highly centralised health systems can impose a structure on their cancer services from above. Where no such powers exist, there are a variety of ways to move towards greater referral of patients to specialist centres.

- Insurance companies can refuse to pay for patients to be treated at hospitals that don't meet certain quality criteria – including minimum volumes.
- Professional bodies, like EUSOMA, can define minimum criteria.
- Patients can boycott hospitals that don't fulfil minimum criteria.
- Hospitals can choose to refer patients to the nearest major centre, or call in surgeons from more specialist centres.
- Hospitals within a given region can club together and decide which will specialise in what; they can refer patients between themselves.

Spread the word

→ Emma Mason

Specialising in a cancer with very poor prognosis, **Heine Hansen** is as keen as anyone to find new therapies that can improve survival. But he also believes that significantly better results could be achieved using currently available treatments, if only everyone knew about and followed best-practice guidelines – and he has done more than most to ensure they do.

Heine Hansen initially considered using his considerable talents to tend the forests of his native Denmark. Happily, he opted instead to go into medicine, where his efforts to improve the quality of cancer care have had an impact worldwide.

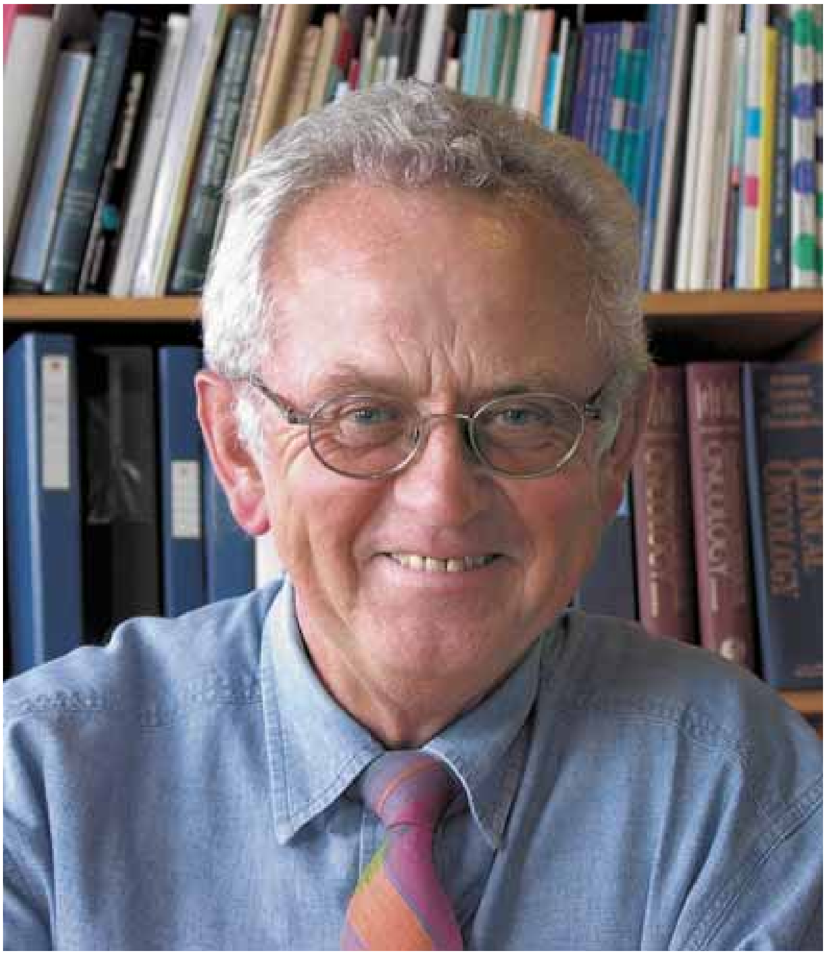
A revealing moment came during our interview for this article when Hansen reached for his collection of photographs and chose a group shot of himself with Eastern European colleagues in preference to an image of himself alone. Team building and working has been a central theme throughout Hansen's career, and he had to be encouraged to hunt out the portrait photo shown opposite.

Hansen believes that it is through building strong relations at national and international levels with other medical professionals (physicians, nurses, basic and translational researchers) and decision-makers, as well as, importantly, with patients and their families, that progress can be made in finding better treatments and cures for the range of diseases that makes up cancer.

Hansen chose to specialise, early on in his career, in one of the most intractable and difficult to treat – lung cancer. Now, aged 68, and with a personal chair as Professor of Clinical Oncology at the University of Copenhagen, Denmark, he looks back over the past decades and sees three important threads running through his work: lung cancer, the search for new drugs, and the importance of communication at all levels through team working.

"I have been lucky that I have had, and still have, very good co-workers around me, so we are a team, and team work and team spirit is an important part of one's professional life, particularly if you have activities that you want to initiate and you want to implement," said Hansen.

The activities he has initiated and achieved through his team working and networking have related to pursuing better treatments not only for his own patients, but for patients Europe- and world-wide, via international collaboration. He was a founder member, office-holder and moving light of the International Association for the Study of Lung Cancer (IASLC), an active



and influential member and office-holder of the European Society for Medical Oncology (ESMO), and a member and office-holder of other organisations too numerous to list here, but which include the Danish Cancer Society, the American Society of Clinical Oncology (ASCO), and the European Organisation for Research and Treatment of Cancer (EORTC).

That all patients, wherever they are, should receive the best possible treatment and management of their disease, irrespective of their social and financial status, is an article of faith with Hansen. He believes that if people can gather evidence about what cancer treatments are working best in which countries, and then present this to the decision-makers, change will be more likely to happen. This task of informing doctors, patients and decision-makers is what he has been doing through the IASLC and ESMO.

"The impact, the impression, is bigger than if individual physicians say 'we want that'. This is the force of working internationally and working with guidelines that are common across Europe, for example. In general, physicians are not using sufficient time to discuss these items and let the decision-makers understand what the situation is. Sometimes they are too busy doing other things, but this aspect of presenting information is very important," argued Hansen.

A GLOBAL CURRICULUM

Hansen counts his work on this as a key success in his career. Probably it is best illustrated by his development of the Global Core Curriculum in Medical Oncology – the result of collaboration between ESMO and ASCO, which started life as an initiative to help colleagues in Eastern and Central Europe.

"We set up the Task Force for Central and Eastern Europe just after the Berlin Wall came down, because we felt there was a need to get out and see what was the situation, what were the options, how could we meet, how could we assist them (if they wanted – and that's

"Physicians are not using sufficient time to let decision-makers understand what the situation is"

A job well done. Heine Hansen founded ESMO's Task Force for Central and Eastern Europe in 1996. It was wound up at a farewell symposium at the ESMO congress this September, its task having been successfully concluded. The Task Force is pictured here at its second meeting, held in 1997 in Copenhagen. Hansen is seated on the left

important) not with money, but with knowledge, experience and so on."

Hansen's aim was to be guided by his Eastern European colleagues, and for them to say what they needed, rather than have help imposed on them from outside. Together they set up a series of meetings and courses that were open not just to medical oncologists, but to nurses too. "This was unusual in Eastern Europe at that time, when the physician was king," said Hansen.

The meetings revealed the need in Eastern Europe for clinical recommendations for cancer treatment to help with the education and training of medical oncologists and to influence decision-makers. "This is what ESMO has developed since. It has been used in the arguments in individual countries to improve treatment and to help the politicians and decision-makers get to the point where they have to say 'well, we are part of Europe, we are going into the EU, we also need to improve our healthcare system and see what is happening in the other countries.' This was what gave us the idea for developing a core curriculum not just for Eastern Europe, not a European one, but a global one."

So, out of the needs of Eastern Europe was born an initiative which would help medical oncology around the world, and which has assisted in another aim – that of having medical oncology recognised as an independent speciality in Eastern Europe; Bosnia-Herzegovina, Croatia, the Czech Republic, Hungary, Latvia,

Hansen's aim was for them to say what they needed, rather than impose help on them from outside

Out of the needs of Eastern Europe was born an initiative that would help oncology around the world

Poland, Slovakia and Slovenia all recognise medical oncology as a specialty now.

The Eastern European initiative is an example of Hansen's ability to capitalise on current events. Another example comes from the beginning of his career, when he started to specialise in lung cancer at a time when few people were interested, because survival rates were so poor that it seemed pointless.

Hansen's medical career started when he had to choose between studying forestry or medicine after leaving high school. Influenced by a friend's medical textbooks, he chose medicine and went to the University of Copenhagen. However, his interest in the natural world has persisted throughout his life. He loves gardening and he owns a summer house on the coast where he goes fishing.

Having chosen a career in medicine almost by accident, Hansen said: "It was chance that I went into oncology." After completing his medical degree and spending time in the air force, he married Lise, who is a nurse. They both felt it was too early to settle down in Denmark, so, at the suggestion of a family friend, he obtained a post in the haematology department at Montefiore Hospital, Bronx, in New York.

The year was 1967. "This was the period when there were major advances in the treatment of haematologic malignancies." These advances had stemmed from the discovery, during World War II, that mustard gas lowered white blood cell levels, especially lymphocytes.

"In 1967 I saw patients up in New York with lymphomas who were treated with chemotherapy, and I saw dramatic activity. So this was exciting."

A year later he was appointed to a new ward that was being set up by the National Cancer Institute, in collaboration with the VA Hospital, in Washington DC to explore the use of chemotherapy in tumour types that were common in war veterans, such as lung cancer. "During this period I got started on clinical research, and that included, first of all, lung cancer, but also new drugs, and these became the two main lines of my clinical research, which continued after I came back to Europe.

LUNG CANCER IS NOT JUST LUNG CANCER

"We observed that lung cancer was not just lung cancer. We identified small-cell lung cancer as a special clinical disease entity. Small-cell lung cancer has certain characteristics that make it different from the other histologic types. There are two very typical characteristics that we identified during that period, and these were that it has a tendency to spread early and wide. This we detected by doing routine evaluation of the patients by bone marrow examinations and laparoscopies with scopes and biopsies from the liver. So we found out that these patients had much more disease at the time of diagnosis than one would otherwise expect.

"The other particular aspect of this disease is that it is very chemo-sensitive. At that time it was identified as the most chemo-sensitive of all lung cancers. If you don't treat small-cell lung cancer, the majority of the patients die within a few weeks.

"We started to give first one drug, then two together, then three together, and we saw that a lot of patients responded to the treatment and they got better clinically, and their symptoms disappeared. But unfortunately, as time went on, the tumour recurred. But at that time, what was important was that we could identify a group of lung cancer patients where chemotherapy had an effect, and a worthwhile effect."

Hansen wrote many publications on lung cancer and new drugs at this period, followed by a doctoral thesis on bone metastasis in lung cancer after he returned to the University of Copenhagen in 1973 – where he has remained ever since. It was while he was in Washington that he first started his international collaborations, setting up a trans-Atlantic study between the NCI and the Mayo Clinic and the largest clinic in Cape Town in South Africa. "This was very unusual then," said Hansen. "But it worked out. We treated patients the same way, with the same drugs, same doses, we had a protocol and we published together. And that was really the background for creating the IASLC. That has led to many years of work for me, in lung cancer, at an international level."

SPREAD THE MESSAGE

Hansen was executive director, founding editor, and chief editor of the journal *Lung Cancer* for 20 years, and president of the IASLC. "We set up a lot of activities around the world to spread the message about lung cancer, that there were treatments, that there were different treatments for different types and stages and so on. It provided the opportunity to meet on a global basis, because lung cancer is a global disease."

More than 30 years on, there have been small improvements in the treatment and survival of lung cancer, but there has been very little improvement in five-year survival rates, which are still poor, ranging from around 5% to 15% in different countries.

Surprisingly, perhaps, Hansen does not find it depressing to specialise in a disease where the prognosis for patients is so poor. This is partly because he treats a range of other tumours too, such as testicular and ovarian cancers, which have much better survival rates. But it is also because he knows that, while he may not always be able to cure his patients, he can offer them the best care possible in the meantime.

"With the lack of success we had, one had to realise that it's also important that, independent of whether the patients get cured or not, the majority of cancer patients need professional management. During the period that they get treatment, and also during follow-up, they need a lot of support, their family needs support and, again, you need teams, you need physicians, you need good nurses, who all have to work closely together. Of course, sometimes when you go home you feel the pressure, you feel it's been a tough day." Being able to talk with Lise helps him to unload the day's problems and he values her perspective on patient management.

There is no doubt that Hansen is a very patient-focused physician. "If everything goes wrong, you can always go down to the patients and be around the patients and then you get extra strength to keep going, and that is why I am still seeing patients." He holds a clinic twice a week, in addition to his other duties.

Hansen is optimistic about the future for lung cancer patients, although he doesn't expect dramatic improvements in survival in the short term. For a start, their public profile is rising and they are less likely to be regarded as low priority because of smoking, social class and low survival rates.

"Things are changing for the better. More and more resources are going into basic and clinical research and we have also seen better results in the last decade than previously. But there's a long way to go, and for that reason we really have to focus on prevention."

As with many other cancers, biological therapies, with treatments tailored to the individual patient's genetic profile, are the way forward for lung cancer, Hansen believes.

"There are some drugs available already that are changing the overall treatment of lung cancer. At present, it is mainly in advanced disease, because that is where the clinical trials have taken place, but that is changing. Drug companies know lung cancer patients are a large group and worth investing in, so they are working on developing better agents, that are better tolerated, have fewer side-effects and can be taken in tablet form, for instance, rather than intravenously."

GET IT EARLY, TREAT IT WELL

There is one key aspect of lung cancer that can make a significant difference in survival rates: how early the disease is detected and how aggressively and competently it is treated. One of the reasons why the US has better survival rates than Europe, Hansen believes, is because patients go to their doctors earlier and then their disease is treated more quickly and more aggressively.

Best practice is the same in any language. The development of the ESMO-ASCO Global Core Curriculum in Medical Oncology grew out of Hansen's concern to offer assistance to oncologists in Eastern Europe

"In Europe you often find a negative attitude to diagnosing and treating lung cancer from many physicians, because they think survival rates are so poor that it doesn't really make any difference. In the US, the attitude of doctors and patients is somewhat different. Technically they are ahead of Europe, and when patients have symptoms they get a better work-up, they are referred to the right specialist, and they will probably be treated by a multidisciplinary team including a chest physician, surgeon, radiotherapist and medical oncologist.

"In Europe, if a patient comes in with some modest symptoms, doctors will often take a 'wait and see' attitude, which means that lung cancer is diagnosed later, when it is harder to treat. This is a crucial difference, because if lung cancer is detected early, the five-year survival rates, while not impressive, are about 50% for early cases. If the patient has gone to the right place, at the right time, with the right stage [i.e. early-stage cancer], then they have a good chance of a cure."

At home, one of the ways that Hansen is making a contribution to improving Denmark's cancer survival rates is as a scientific advisor in oncology to the Danish Health Authorities. Together with a colleague, Hans van der Maase, he co-ordinates a panel of experts to whom individual doctors, hospital departments or even patients can appeal for advice on the best treatment for a particular cancer. This 'second-opinion' panel makes recommendations that may uphold the current approach, but equally can recommend a different approach, a different drug, or even a different hospital in another country that can treat the disease better. Patients can then have access to these treatments completely free. This scheme has only been running for two years, but already Hansen believes that it is making a difference not only to patients, but also to translational research, because the panel co-ordinates six new experimental units as well. In addition, it helps to inform doctors about the latest treatments.

"Already there are disease entities which we can treat that we couldn't two years ago," he said. He counts the panel of experts scheme as one of his successes, and hopes the idea might spread internationally.

Hansen says he is cutting his work back a bit so that he has more time to enjoy his family. He and Lise have two children, a son, Thomas, and daughter, Marie, and two twin grand-daughters, Frederikke and Rosemarie, with another grandchild expected later this year. "What I do in the future depends on the situation, on ideas, and whether I think I can make a difference. If you still feel that you can offer something, then you have an obligation to those around, because you have a lot of experience that you can offer. But, as Jonas Salk once said: 'Our greatest responsibility is to be good ancestors'."

"If you still feel that you can offer something, you have an obligation"

Record-breaking stamp raises sticky questions

→ Marc Beishon

Concern that vital research is being side-lined for lack of funds prompted US breast cancer surgeon Ernie Bodai to campaign for a special fundraising stamp. Despite the 6-cent mark-up, it has outsold all previous commemorative stamps including one of Elvis Presley. Yet Bodai has met with harsh criticism from some surprising quarters.

What is small, sticky and worth more than $50 million and counting? Answer: America's Breast Cancer Research Stamp, a so-called 'semi-postal' mail stamp that has not only raised millions for cancer research but has also made history by being the biggest-selling 'commemorative' postage stamp in the country's history.

Semi-postals are a simple idea – by adding an extra charge to the normal face value of a stamp, they have been used for many years in other countries to raise money for charitable causes such as the Red Cross, to help pay for various Olympic Games and to support war efforts. After administration costs the rest of the extra goes to the cause – the breast cancer stamp currently sells for 45 cents, compared with the normal 39 cents first-class value. But the breast cancer stamp is a modern phenomenon among semi-postals.

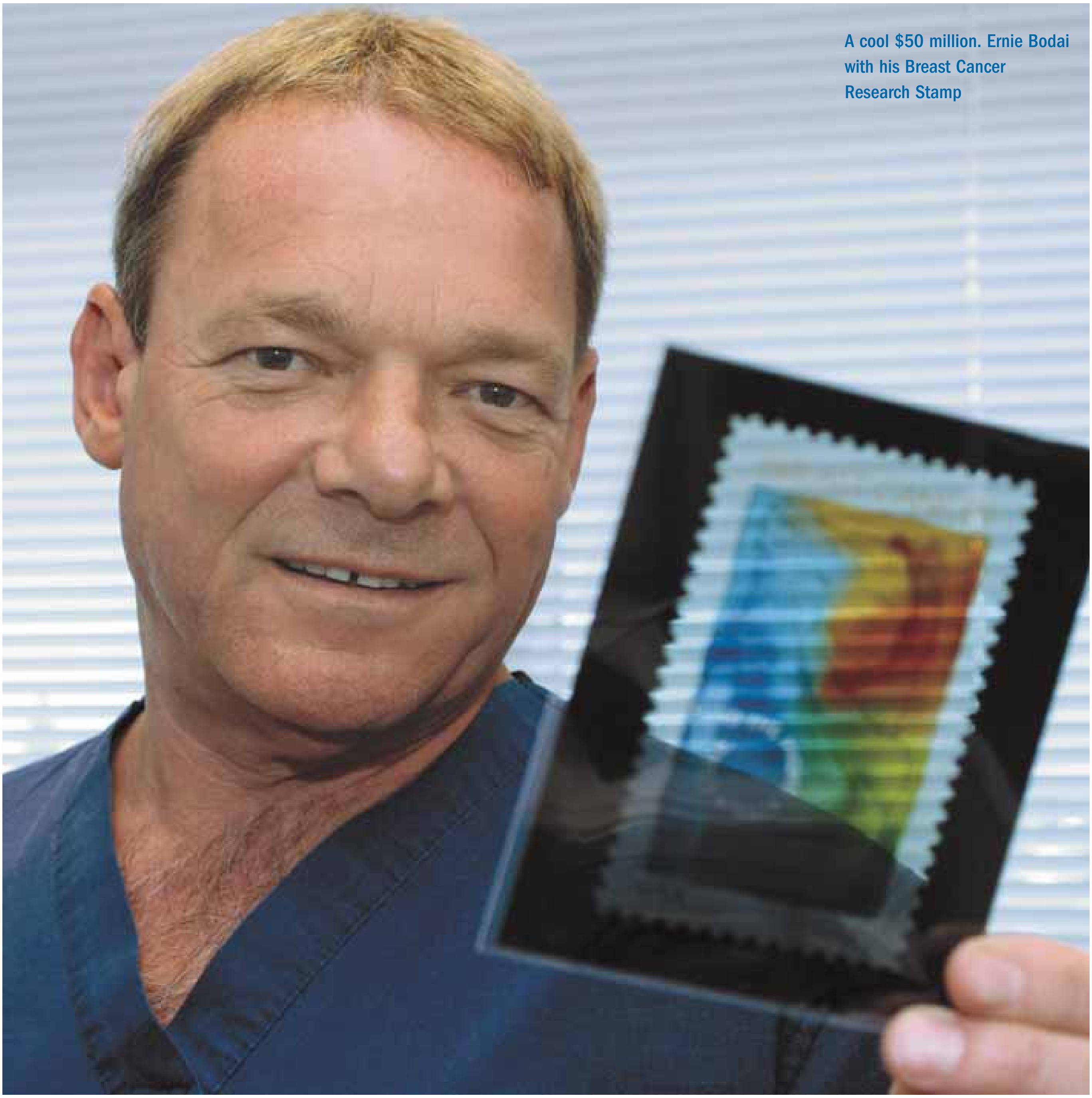
For a start, when it was approved in 1998 it was the first ever semi-postal issued by the US Post Office – by and large, semi-postals have been most popular in Europe. Second, the breast cancer stamp can lay claim to being one of the most popular semi-postals of all time worldwide, capturing Americans' hearts and minds so well that 900 million have been sold – more than a commemorative Elvis Presley stamp of the early 1990s (which was just a standard stamp). And the idea for the stamp came from one man – breast cancer surgeon Ernie Bodai, who surmounted formidable obstacles to get the stamp introduced.

Bodai, who is director of the Breast Health Center at the Kaiser Permanente Point West facility in Sacramento, California, explains how the idea came to him. "I was preparing a lecture on the history of breast cancer surgery and looked into art history – you can trace the history of treatment by looking at often gory surgery artwork going back to ancient Egyptian times. It was then I thought about a stamp for breast cancer – and a moment later, I thought we could price it higher to raise money for research."

A DROP IN CANCER RESEARCH

This was in 1996, a time, adds Bodai, when it was becoming apparent that there was a serious drop in cancer research in the US. "Clinical trials had become much more expensive thanks to a growth in paperwork and the sheer cost of the new therapies that were coming out. While in the early 1990s we were funding 70% of all proposals, today it's in the 20% range. There just is not enough money to fund studies – and what if one that gets turned down has the crucial piece of information we need?"

It is this nagging thought that has driven Bodai in his stamp quest – that and the lack of progress in breast cancer treatment, typified by the long



A cool $50 million. Ernie Bodai with his Breast Cancer Research Stamp

> "While in the early 1990s we were funding 70% of all proposals, today it's in the 20% range"

“Many of the grants are for around $100,000, and have gone to scientists who are not yet established”

procession of women presenting at his clinic for surgery. With this aim, and realising it would take a Government Act for the US Post Office to issue its first semi-postal, he initially wrote to more than 50 women in Congress and the Senate – and received absolutely no replies.

That made Bodai “furious” and was the start of a virtually one-man campaign to lobby for the stamp. Although he received some help from certain people, in particular cancer survivor Betsy Mullen, who had formed a women’s breast cancer information group, Bodai says he was more or less on his own as he trod the corridors in Washington in a two-year campaign that was hugely costly in terms of his energy, time and expenses.

The painful details of how Bodai managed to get support for the stamp and see it through to a Government Act – the Stamp Out Breast Cancer Act – and the issue of the stamp in 1998 have been written up extensively in the US. Much of the story is about how someone with no lobbying experience goes through the steep learning curve of working out just how to get one government bill onto the books ahead of the many hundreds put forward each year. Bodai says he enlisted the help of his own profession – the cancer societies and the American College of Surgeons – to write to Congress, and he and his close lobbying colleagues made early breakthroughs in gaining the support of congressmen and women whose own lives had been affected by breast cancer.

But two issues stand out for Bodai, particularly as he is now working to help introduce semi-postals in other countries. The first is the likely attitude of a post office. “The big fear of the US Post Office, and of other post offices I have dealt with elsewhere, is that if they start a breast cancer stamp, they will have the Alzheimer’s, heart disease and lung cancer people come after them as well, and most post offices do not want to be bothered with fund raising.”

Indeed, the US Post Office has been inundated with requests for semi-postals for many other causes, and two others have since been issued – one for the victims of the 9/11 terrorist attack, the other for domestic violence. But back in 1996, the Post Office, says Bodai, was opposed to issuing its first semi-postal and even issued a non-fund-raising breast cancer awareness stamp of its own the following year, “trying to derail my stamp. It didn’t work.”

TERRITORIAL DISPUTES

The second – and still ongoing – issue has been a lack of support from the very organisations Bodai thought he could rely on, namely the large breast cancer charities. For Bodai, this is a straightforward territorial dispute. “Several influential organisations that should have supported us didn’t, because they weren’t going to be the recipients of the funds,” he says. “Most of these organisations are run by strong female personalities and they also don’t like me because I’m male. “I put great effort into establishing relationships with them as I really needed their help with lobbying, but every time I went to Washington they thought I was stealing their thunder. I even said, ‘I’ll give you the project and never come back if you get the job done.’” The largest such charity, the National Breast Cancer Coalition (NBCC), is the one he has most in mind.

While not opposing the stamp, Fran Visco, NBCC’s president, comments: “We feel that the stamp doesn’t raise much money and abrogates the US Congress’s duty to appropriate sufficient funds for breast cancer research. It is a band-aid that makes Congress look good, others feel good, but doesn’t really do enough. We do not support the effort, in part because we only support those efforts that we believe will have a major impact on breast cancer. The stamp does not fall into this category, and, in our opinion, fails to effectively raise the public awareness of the vast resources needed to eradicate breast cancer.”

Naturally, Bodai disagrees. The stamp, he says, has played a big part in raising awareness – the many millions sold is testimony – and while the $50 million raised for research may be a relatively small slice of breast cancer funding over the last decade, it has gone to important work. The money is channelled via two bodies: 70% to the National Institutes of Health/National Cancer Institute (NCI) and 30% to the Department of Defense’s (DoD) Medical Research Program. It has largely gone to research programmes outside mainstream funding, such as the NCI's Insight and Exceptional Opportunities awards, and the DoD's Idea awards.

Many of the grants, says Bodai, are for amounts around the $100,000 mark, and have gone to new scientists who have not yet established themselves, "Not to the good old boys' club who get the same money every year from the same places. And in the GAO's report there is a list of six major advances that have been funded by the stamp." (The GAO – US General Accounting Office – produces reports on the effectiveness of the fundraising stamps; approval for the breast stamp has to be renewed every two years.)

This research includes the identification of new proteins not previously known as autoantigens of breast cancer, a new molecule that inhibits the activity of epidermal growth factor, and a new tumour suppressor gene deleted in many breast and ovarian cancers, related to a gene known to be important in identifying colon cancer. Many of the research studies, adds Bodai, could be important for cancers other than breast.

A GLOBAL JOURNEY

Bodai has barely let up in his crusade since the stamp was first issued, travelling to many speaking events, setting up the Cure Breast Cancer Foundation (www.curebreastcancer.org) as an organisation behind the initiative, and helping to promote the stamp worldwide, the 'global journey', as he calls it. Olivia Newton-John's charity, the Liv Foundation, is a partner in this global effort. A semi-postal has been issued in Hungary using the same design as the US – Bodai was born in Hungary and came to America as a child – and he says there are also plans in Romania and Slovenia. He also became a cancer sufferer himself – he was diagnosed with prostate cancer in 2000 and certainly supports the introduction of a stamp for this disease, noting that its profile (in numbers affected) is similar to breast cancer in the US.

He's grateful to corporate sponsorship that has helped offset some of the many thousands of his own dollars he has spent, and companies such as Kellogg's have also featured the stamp on their packaging – promotion worth millions. But there are wider questions about the stamp and the 'business' of breast cancer charity generally, explored in a new book by Samantha King, professor of kinesiology and health studies at Queen's University, Kingston, Canada, entitled *Pink Ribbons, Inc.: Breast Cancer and the Politics of Philanthropy*.

Says King: "Breast cancer has been transformed into a market-driven industry. It has become more about making money for corporate sponsors than funding innovative ways to treat breast cancer. Fundraising for breast cancer has developed into a highly competitive market in which large foundations and corporations compete with one another to attract the loyalty of consumers – in this case, well-intentioned members of the public wanting to do their part in the fight against the disease."

HARD TO SAY 'NO'

In a chapter devoted to the breast cancer stamp, King writes that it soon became a bipartisan, politically acceptable measure that was "hard to say no to" (especially because it helped shift the onus from the state to volunteerism and consumerism). The stamp, she argues, is just more of the same in America's history of 'big spending' on cancer research and the recent rise in the 'pink ribbon'-style awareness industry, rather than "evidence of a widespread and new found concern about the disease". Breast cancer politics, she says, can instead become very partisan if issues such as health inequalities are raised. "The stamp became … a mechanism for limiting how people think about, speak of, act upon, and constitute the disease," she concludes.

Bodai is unconcerned by such controversy, and indeed notes himself the infighting for funds and kudos among breast cancer and other 'disease' charities. He recognises that much more needs be done to address America's health inequities in breast cancer, but is unrepentant about the basic research funded by the stamp. Given the struggle to get the funding stream running, he's not about to rock the boat in the US, but says other countries can and should channel funds toward better treatment and screening.

And before the Internet wipes out the postage stamp for good, Bodai – in a still largely one-man effort – will continue to enthuse others in the worldwide research community to post their desire for a new source of funds.

"The stamp became … a mechanism for limiting how people think about ... and act upon the disease"

Helping the media to get the message

→ Peter McIntyre

How do you report on an issue that is publicly taboo and personally sensitive, and where the data are scant and the professionals can be unhelpful? Seven journalists who gathered at the UICC conference in July found they could learn a lot from one another.

There is a smattering of applause in the airy press room of the Washington Convention Center as today's headlines ticker across the bottom of the television screen. CNN has picked up the news that a billion people will develop cancer this century, unless something is done.

Around the room, journalists are filing stories from the World Congress of the International Union Against Cancer (UICC). Some of these journalists work for media in Africa, Asia, Latin America and Central Europe, countries where up to 70% of new cancers occur, but where cancer is often seen as a non-issue.

This mismatch prompted three organisations to support health journalists from these countries to attend back-to-back conferences in Washington DC in July – the UICC World Congress, and the Health or Tobacco Conference – to develop their knowledge.

The American Cancer Society (ACS) the European School of Oncology and the UICC selected journalists from daily newspapers, TV, a news agency and a specialist magazine:

- Jacqueline Montes Eguino, reporter for *La Razon* newspaper in Bolivia
- Kristina Baxanova, reporter for bTV Balkan News Corporation, Bulgaria
- Ashraf Amin, assistant head of the science desk on *Al-Ahram* newspaper, Egypt
- Yaa Oforiwah Asare-Peasah, deputy news editor of the Ghana News Agency
- Viktoria Kun, reporter for *Nepszabadsag* newspaper, Hungary
- Conrado Generoso, editor in chief of the *Medical Observer*, in the Philippines
- Timothy Makokha, deputy health editor of *The New Vision* newspaper, Uganda

All these journalists know that cancer is highly significant in their countries, but is given little priority compared with HIV/AIDS, TB, malaria, diabetes, and diarrhoea. Public awareness of cancer is low, while fear and stigma inhibit discussion. The journalists accept that the media must bear some responsibility.

Jacqueline Montes Eguino says: "The media is not doing its job. We do not have enough articles talking about cancer. People with cancer don't have access to surgery or medicines and, unfortunately, they just die. In rural areas people think they can use traditional medicine and a poultice."

Most people seek treatment far too late, and so, says Timothy Makokha, cancer is seen as "one disease that consigns you to an early death". Viktoria Kun agrees. "If you say 'cancer', most people understand 'death', but when you know about this subject you can face it much better."

JOURNALISTS LACK ACCESS TO DATA

If journalists are to play their part in combating fear and stigma, they need access to facts and to experts. When

PETER MCINTYRE

On the job. The seven sponsored journalists filed stories to their newsrooms from the UICC and Tobacco or Health conferences. The trip provided an ideal opportunity to find out more about cancer, and to discuss with colleagues about how to improve media coverage of the disease. *From the left:* Jacqueline Montes Eguino (Bolivia), Conrado Generoso (the Philippines), Kristina Baxanova (Bulgaria), Timothy Makokha (Uganda), Rennie Sloan from the American Cancer Society, Ashraf Amin (Egypt), Viktoria Kun (Hungary), and Yaa Oforiwah Asare-Peasah (Ghana)

journalists lack access to basic information, this contributes to one-dimensional reporting that stokes public alarm rather than improving awareness.

Conrado Generoso says: "Journalists who write for the tabloids or television often get their facts wrong and give people wrong information. The health community has to help to train journalists on health reporting so they can understand what doctors talk about and translate the stories into something the layman can understand."

Kristina Baxanova believes that the media often tells only one side of the story – failing to highlight the benefits of treatment and prevention. "In Bulgaria most people understand this as an incurable disease. Most stories we cover are about bad examples. We also need to cover good examples of how to prevent or cure or talk about cancer."

But it can be difficult to find the facts. From Uganda, Makokha complains of "stifling bureaucracy, unnecessary secrecy and a deliberate unwillingness to give information". By the time a journalist has obtained permission to access information, the deadline for the story has often passed.

Official information is of suspect quality. Generoso says: "In the Philippines even data on cancer incidence is hard to get from government health agencies – and is often outdated. There is no centralised agency that collects data and makes them available."

Ashraf Amin points out that in countries like Egypt, with no national screening programme, data about cancer are often derived only from patients seen at national hospitals or from WHO estimates. In Bolivia, too, the pattern of disease is clouded. "There is no official information or statistics about cancer cases, because most of them are treated by the private sector or by traditional medicine," says Montes Eguino.

ETHICAL ISSUES

Journalists, just like doctors and nurses, face ethical problems daily, with pressure put on them from outside forces, and by a natural tension that exists within journalism between the need to make headlines and the need to protect people from harm.

There is a particular problem when companies or individuals promote drugs or treatments, and even responsible reporting can fuel demand which poorer countries have no way of meeting.

Kun, who won an ACE (Awarding Cancer Enlightenment) award for her articles about the situation in Hungary, sees a need to balance stories about scientific advances with an understanding about the availability of treatment. "I have ethical problems because there are many people who cannot access these medicines. Recently, a professor came to Hungary and was 'selling' a story about a wonder drug. I was against publicising this because it puts a wrong idea into the heads of patients. But I could not do anything. They saw this on TV as a wonder medicine."

Amin points out that journalists are not in a strong position to know who provides good treatment and who is making extravagant claims. "The media has a problem because many people claim to have cured cancer. And sometimes people's cancer does seem to have been cured. We are not doctors and we are not able to say what is scientific and not scientific, and the doctors themselves are not that confident about it."

Another issue is the extent to which it is right to use individual human stories to make articles about cancer more interesting.

Generoso encourages his journalists to humanise stories with the consent of the individual and their doctor. "Don't tell me that 8,000 people die of breast cancer. Find me one person and put a face to the story." To some extent, says Viktoria Kun, this can benefit the patient. "Often people say that they feel better because they could speak to someone." Yaa Asare-Peasah believes that human stories also help people make good choices. "We have to tell the story to explain why you should go to the doctor."

But Montes Eguino does not agree, and her paper, *La Razon*, does not use individual patient stories in this way. "Of course it makes more impact to use one case, but we don't do that in my paper. We write about the situation generally, not about individuals."

Amin sees another dilemma. "I am ashamed to say that rich and powerful people do not appear on our screens; it is just the poor people who do not have the means and facilities. The NGOs put patients on the media to get more money. We take pictures or show how a mother is suffering. The patient did not really have a choice. They have been used. I do not know if it is ethical or not."

Television reporter Baxanova believes that journalists face a difficult choice. "There is still a lot of stigma attached to cancer. Patients are often shy and afraid to talk. I show the back of the head, or interview the doctor. But if we want to influence people and be more effective, you have to show people. If you show only statistical data and doctors, it is not easy for the audience to understand."

SCIENTIFIC LANGUAGE BARRIERS

There are technical problems for journalists in non-English speaking countries, as most research material is in English, and reporters need a high level of skills to access this, to understand and to explain it in their own languages.

Amin, who writes for a mass-circulation Arabic paper in Egypt, says that this can lead to conflict between journalists and doctors: "Most journalists do a double job as journalists and translators, searching for the easiest term for the readers and giving the scientific meaning for the doctors. Most scientists want to see it in the paper with all the scientific details. As a journalist, we have to make it readable. Sometimes the text is accurate but not readable. Or sometimes journalists do their work and make it readable, and scientists refuse to be interviewed and say that media people are not accurate."

These issues are poorly understood by doctors and nurses, who often steer clear of the media and have little confidence in dealing with journalists. But by working with journalists, they can affect the way that cancer is reported.

CHANGING PRIORITIES

Certainly, Baxanova felt that her own priorities had changed from intensive exposure to global experts at the Washington conferences. "I can show that if we can treat cancer early, we can have incredible results. I was very interested in the vaccination programmes. I think I should be stronger in fighting to do stories on these issues."

Asare-Peasah said it had broadened her horizons. "I have done health reporting for many years, but this has been an eye opener. It makes me think that in Ghana we are far behind on a cancer control programme. I am going to focus a lot more on cancer issues in the future. Media reporting is very poor compared to other health issues."

For Generoso, the conferences highlighted an imbalance in global news coverage. "We get the news through news agencies about breakthroughs in the developed world, but very little about what is happening in Africa. That was an eye opener. We hear about AIDS and malaria, but I did not realise that cancer was a big problem there."

Amin believes that journalists can help countries to learn from each other. "I was very touched by the presentations from Africa, as if we were in the 18th century while others were talking about new technology. The main message I come away with is that people are denied treatment and services because of lack of resources. We should be learning from each other and how to help each other. Maybe we don't listen to each other enough."

Reporting cancer from the inside

Catherine Kalamis of the *Guernsey Press* won a Best Reporter Award 2006 for a series of articles based on personal experiences of living with cancer. Below we reprint *A life-changing moment*, where she explains why good information is so vital to patients and she sends out a message about turning a threatening change into something positive.

Last week, a chapter closed as I left the staff of the editorial family that is the *Guernsey Press*. But a new, exciting one starts. I was recently told about a man diagnosed with cancer who decided to ditch his old, safe life and instead live for the moment. He has since travelled the world and experienced many of the challenges he had previously only dreamed about.

I feel a bit like that. This is something that cancer does to you. It still has the power to change the way you feel about life, relationships, faith, self and the part that is frequently entwined in your essence as a person – work. While a growing number of cancer patients can still retain some health and actively live with their disease – which is happening more and more because of improvements in cancer treatments – so more people 'with a diagnosis' are deciding they want a change of direction in their life.

Until now my usual work has been my therapy, giving me grounding during an emotionally rough time. Holding on to that has been important to steady myself in the new world of uncertain futures. It's important for employers to be understanding during this phase and, fortunately, mine has been. But now the time has come to make a change, to break free from the safe, or the 'same old, same old'. So I am now fulfilling a goal to achieve something meaningful for cancer patients.

Three of us are launching a brand new patient foundation for people diagnosed with neuroendocrine tumour [NET], the little known and relatively rare form of cancer I was diagnosed with last year. It sounds a simple idea but already it's proving quite a mammoth task, with 48 pages of admin to plough through, a business plan to prepare and a legally binding governing document to write before we can apply for registration with the UK Charity Commission. And that's before the really demanding work begins. But why, when there are hundreds of other

The Guernsey Press and Star

Good news. As a patient, Catherine Kalamis has used her own cancer diagnosis as an opportunity to refocus her life. As a journalist, she has used her pages in the *Guernsey Press* to tell her readers about the experiences of patients and their families, and to send out a message of hope: there is life after a cancer diagnosis – and it can be pretty good

HEALTH

A life-changing moment

There is no doubt that a cancer diagnosis changes lives. But sometimes it can be positive and life-enhancing and takes you in a totally new direction, as **Cathy Kalamis** explains

'I shall be moving to a new sort of work, following the lead of many others who have been diagnosed with a shattering illness and yet found a way to move forward positively'

cancer charities? There is a simple answer. My experience showed me that there is currently very little information 'out there' about NETs.

I found a lack of general, lay information when I was eventually diagnosed with a NET in February 2004, three months after first falling ill. There is some to be found on specialised medical websites, or those created by drug companies. There is a bit more info about a specific type of NET called carcinoid tumours, which are the most common of the group – there is even a New York based group called the Carcinoid Fighters – but there is no centralised information about neuroendocrine tumours as a whole.

I have discovered in the past year that although this type of cancer can affect children, there are no paediatric specialists in the country and no specific information for parents. And there are only 12 consultants in the UK who have an interest in the disease, but they also do a lot of other work. My experience is not unique. I have since met many others who were presented with a shattering diagnosis but found it hard to access solid, meaningful information, especially at a time of great distress and anguish.

Then there were family and friends. None of mine had ever heard of neuroendocrine tumours and all of them expected me to have the 'traditional' treatments of chemotherapy and radiotherapy because they heard the word 'cancer'. They still ask me about my treatment when, at present, I am not having any. I had to find out bit by bit and use my own words to explain that these tumours are, generally, slow-growing cancers even when they have metastasised to other sites in the body, which is what has happened in my case.

And chemo and radiotherapy, although useful for some patients with aggressive disease, might not always be the first-line course of treatment immediately after diagnosis. There are, however, other treatments and it's a judgment as to when they are brought into play. None of this is very easy to explain to someone who just asks about your welfare. Every clinic I have attended has been oversubscribed and it is common in

One of the real issues affecting NET patients is a feeling of isolation

the UK that the doctors don't have much time to go through everything, or repeat it until it is fully understood.

NETs can become more aggressive, so patients need continual monitoring with scans, blood and urine tests to watch for the signs. Another peculiarity is that tumours can express high levels of hormones, but it's not always that straightforward, and some types don't. Although around 2,000 new cases are diagnosed each year in the whole of the British Isles, it is thought there are many people who have a NET but don't yet know it. I could have had mine for a decade or so already. If only there was some way of detecting them more quickly, then patients could have surgical intervention and perhaps even a cure. But the vast majority of patients who seek specialist referrals have metastatic and often inoperable, and therefore incurable, disease.

Speaking to other patients waiting in the NHS [National Health Service] clinic in London, I learned that it had often taken them years before getting a proper diagnosis. The common story was that GPs [general practitioners] or even specialists had dismissed their vague symptoms as irritable bowel syndrome or, in one alarming case, as being 'all in the head'. So the more I discovered about my disease the more the gaps in information, awareness, and understanding became acutely obvious.

A dynamic specialist NET nurse has had the same thoughts for years. She had been dreaming of providing more information for patients, but she was simply too busy, with some 550 people on her books. Then I met another patient, who coincidentally had just given up his job in medical PR at a time when I was considering taking my own 'gap year' to regroup and rethink. The three of us spoke many times on the phone and we even had a two-day meeting here in Guernsey.

In September [2005] I took the bull by the horns and approached a world-ranking sportsman – the snooker player Paul Hunter – who had publicly revealed he was suffering from the same disease. At the RAC club in Pall Mall, London, we all met and talked. He has since offered us several thousand pounds from his charitable resources to start what by now we had named the NET Patient Foundation. From there we have not only had his offer of help to publicise NETs, but also the first public fundraising event (when he switched on the Batley Christmas lights and a street collection was held for the foundation), and there is the possibility of a celebrity ball in September, the organisation of which may be filmed for TV with all proceeds coming to the foundation.

We shall see how this translates, but it looks and sounds promising. Suddenly the words and ideas have turned into something real. And now the hard work begins. From a starting position of nothing, we have enough for phase one of the foundation's plans, to obtain charity registration in the UK, approach and appoint trustees and a high-profile patron and begin to put together accurate, impartial and, hopefully, empowering information.

The NET Patient Foundation aims to have a new magazine for sufferers and their families that will not only explain the disease, but offer many practical ways to live positively with it. We want to build a state-of-the-art website and launch a moderated patient forum where patients from across the country – later Europe, we hope and who knows, globally – can talk to each other. One of the real issues affecting NET patients is a feeling of isolation. Unlike breast cancer patients, you probably won't find a large number in your town or village – here in Guernsey there may have been three or four in the past few years. But you could be talking about a larger regional number, and so the foundation aims to organise a national road show, setting up regional patient support groups with the support of the specialist consultants who, we hope, will back us.

And then there are future campaigns that need to be organised – to raise awareness in the general population about the disease as well as front-line health professionals. And to support patients who find they are subject to the 'postcode lottery' for drugs prescribed to control hormonal surges that some tumours can produce. In some areas of the UK, health trusts refuse to pay for these injections even though they immeasurably improve the quality of life for some people.

This has all come about because of my own diagnosis of a life-threatening illness for which there is no current cure. It brings matters sharply into focus. It has become clear that living 'in the now', for the minute and the moment, is what should be important, and following your dreams and ideas, however large or small, should always be a possibility. I am not going to totally give up writing for the *Guernsey Press* – writing for newspapers has been my life for 30 years and it's a hard drug to give up – but I will have more flexibility and it may not be quite so often.

But I shall be moving to a new sort of work, following the lead of many others who have been diagnosed with a shattering illness and yet found a way to move forward positively. Lance Armstrong and Jane Tomlinson* are two such examples although I would never hope to aspire to what they have achieved. My goals are more modest. Armstrong, the Tour de France champion who has overcome a terrible cancer prognosis, has become a champion for cancer 'survivors' and is devoting himself to spreading the word about living well with a diagnosis. Briton Tomlinson, who has terminal breast cancer, has raised a million for charity and taken on the most gruelling sporting challenges. I am not quite in their league, but they show that things can be done even when you have disease.

However, I do want to use my experience to hopefully help create something positive for other cancer patients. It's a bit like the people caught up in the Boxing Day 2004 tsunami.

They also want to 'do their bit' and are highly motivated, perhaps because it is a way of coping, of dealing with what has happened: all that sadness, death and destruction.

Similar things happen to many of us in the cancer club who can still function, it seems. With cancer there always seems to be someone in a worse position than you but who is coping magnificently and bravely in the face of real adversity. Behind it all is a motivation to improve things for others who come along behind, because of our own, perhaps rather poor, experience.

Look at the Pink Ladies [a Guernsey breast cancer support group] and the work they have achieved locally. Jo Allen is one of the five founding members. She said: "The group has grown bigger than anyone could have expected and now has over 90 members. I was privileged to be actively involved in running this support group from its inception until May this year. I cannot express how important this support is to so many women: we're not just talking about emotional support and the benefit of others' experiences, but also the financial help we provide with complementary therapies and so many other helpful items."

She has found her involvement extremely beneficial. "Why did I get involved? Well because it gave me a great sense of satisfaction knowing that what the Pink Ladies did made a real difference and that the road could be somehow easier for those who were diagnosed after me. I'm also at my happiest when I'm helping others and the Pink Ladies gives the ultimate opportunity to do that." Until you have been through something like this, you cannot understand what it is like. "A diagnosis of any form of cancer really does give you the opportunity to re-evaluate your life and to live for now and that's what this wonderful group of women do, whilst encouraging others in the process." I think that says it all.

---

* Jane Tomlinson tells her own story in *What's brave about having cancer?* p 60

This article was first published in the *Guernsey Press* on 9 December 2005, and is reproduced with permission

The subject is complex, the story is clear

Overblown claims and contradictory messages on cancer can lead to confusion and scepticism. Health journalist **Simon Crompton** was recognised in the 2006 Best Reporter Awards for the clear and informative articles he has written for the Body&Soul section of *The Times* (UK). Below we reprint an example, which throws light on the link between exercise and cancer.

We all know that exercise is good for you. We know that it prevents obesity, which is linked with heart disease, diabetes and some cancers. But what about the idea that exercise protects against cancer, full stop?

The notion that the more you exercise, the more you protect yourself from cancer used to sound dangerously cranky. Not any more.

In the past five years, almost unnoticed, there has been a fundamental change in the scientific consensus about the relationship between cancer and exercise.

Cancer Research UK, the biggest independent cancer research organisation in the world, hasn't exactly been shouting about its new conviction, but the past year has seen it state firmly for the first time that inactivity increases your risk of cancer significantly, even if you're not overweight, an idea that would have been laughed at a decade ago. It isn't just talking about one kind of cancer either. Cancer Research UK is convinced that not moving around enough increases your risk of both colon and breast cancer, and says that inactivity may also be associated with cancers of the womb, lung and prostate.

A turning point came at the Labour Party conference this autumn [2005] when the charity held a meeting launching a manifesto for physical activity at which Professor Ken Fox, a Bristol University researcher funded by Cancer Research UK, stated that "independent of other lifestyle factors, you get a 20–30% reduction in all cancers if you are active."

And, early next year, the charity is to re-launch its Reduce the Risk campaign with "be active" prominent among the more conventional messages to "stop smoking", "eat and drink healthily" and "be sun-smart".

There has been a definite sea change, according to Professor Fox, who runs the department of exercise and health sciences at

THE TIMES

Good advice. Measured and well-reasoned articles like this one are far more effective than any front-page scare story when it comes to helping people understand how they can lower their risk of developing cancer

4 | body&soul news

Seeing the bigger picture

Fit enough to fight cancer

At last, scientists admit that exercise can help to protect against tumours. **Simon Crompton** reports

news body&soul | 5

Try reading the script

the 'soothing potato'

NEW

Bristol University. "There's now undeniable evidence that exercise has a direct effect on cancer, especially colon cancer and breast cancer," he says. "I think the whole issue is just beginning to come on line with cancer research organisations calling for more research on cancer and exercise."

The evidence has been stacking up over many years. The idea that exercise could prevent cancer was conceived 20 years ago, when David Garabrant, a young assistant professor at the University of Southern California, noticed that data on a cancer registry indicated that people who had more sedentary jobs tended to get more colon cancer. "I presented the data at a department meeting and they laughed at me; they hooted," he said recently.

But Garabrant is now a professor of epidemiology at the University of Michigan and his contention has been backed up by study after study. In the 1990s, large studies from Italy and the US indicated that physical inactivity could cause 13–14% of all bowel cancer cases. In the same decade, a series of other studies in highly reputable journals indicated that – astonishingly – being active probably halves your risk of getting colon cancer.

The link with breast cancer has been established more recently. A series of studies between 1997 and 2003, published in established journals such as the *Journal of the American Medical Association* and the *New England Journal of Medicine*, found that being active reduced the risk of breast cancer by 30–40%, and seemed to protect women both before and after the menopause.

Exercise seems to reduce the risk most in women who are active early on in life.

In Britain, a turning point came in 2002, when Professor Fox and his team from the University of Bristol published an extensive review of the evidence on exercise and cancer, concluding that not only could it help people to recover from cancer but the lack of it could be a significant and direct risk factor. This came a year after a review by the Scottish Cancer Foundation and the Cancer Research Campaign came to a similar conclusion on bowel cancer.

On womb, prostate and lung cancer, the evidence is less conclusive, although a recent analysis of nine studies indicated that high physical activity reduced the risk of lung cancer by about 30%. And in a study in the new issue of *Urological Oncology* [vol.23, pp463–464], researchers from the Harvard School of Public Health conclude that regular physical activity slows the progress of prostate cancer and may reduce mortality.

Richard Davison, the director of policy and public affairs at Cancer Research UK, says the organisation's new public profile on the cancer–activity link reflects the number of sound studies carried out in the field – and the number of funding applications on the subject to the organisation. "I think perhaps physical activity has been ignored in the past," he says. "The media tends to focus on diet and obesity, and perhaps it's time that changed."

There may be another reason we don't hear more about the cancer–exercise link. Scientists have a natural fear of overestimating the benefits, when further research is still needed to fully understand the association.

One of the foremost researchers in the field, Dr Anne McTiernan, from the Fred Hutchinson Cancer Research Centre, in Seattle, says her fear is that people will start to believe that the reason they got cancer is that they didn't exercise. In most cases, that's likely to be untrue.

Some researchers, such as Dr Brian Henderson, from Southern California's Keck School of Medicine, are also sceptical about how accurately existing studies have measured the benefits of exercise on its own. It's hard to measure how much exercise someone is taking and to eliminate other lifestyle factors that might affect their vulnerability to cancer, such as diet. Studies need somehow to ensure that they cancel out the complication that obesity is also linked with cancer (see box).

However, even taking such scepticism into account, there has been a significant change in our perception of the disease and its causes. Though lack of exercise is way behind risk factors such as age, smoking and diet, Cancer Research UK quotes estimates that it accounts for 5% of all cancer deaths. So if you want to act on the evidence, its advice on exercise is the same as every other organisation with a health promotion message. Try to exercise more intensely and more frequently than you do now, and aim for at least 30 minutes a day.

But you don't need to be slim for there to be a positive effect, and simply increasing your daily exercise dose by taking the stairs rather than the lift, or going for a walk in your lunchbreak, could make a difference.

This article was first published in Body&Soul, *The Times* (www.timesonline.co.uk) on 3 December 2005, and is reprinted with permission

HOW CAN EXERCISE PROTECT US?

- Exercise can reduce levels of insulin, some hormones and other human chemicals called growth factors, which dictate how and when cells divide. At high levels these substances can encourage tumour growth.
- Some types of breast cancer are linked to high levels of the female hormone oestrogen. There is some evidence that exercise causes a weaker version of oestrogen to be produced by the body, reducing the risk of breast cancer.
- Exercise also stops us accumulating fat. Studies have shown that being overweight can increase the risk of many cancers, including those of the breast, bowel, kidney, oesophagus, and womb. This is because body fat is active tissue which produces hormones, and high levels of some hormones can promote cancers.
- Physical activity leads to more bowel activity, so it may protect against bowel cancer by causing cancer-causing substances in undigested food to pass through the bowel more quickly. Exercise can also protect against bowel inflammation, which can be linked to some cancers.
- Being active may reduce lung cancer risk by improving lung efficiency, reducing the time cancer-causing chemicals spend in the lung and lowering their concentration.

Does chemotherapy given directly to the liver improve survival in patients with hepatic metastasis?

➜ David J Kerr*

A study using hepatic arterial infusion to deliver treatment to colorectal cancer patients with liver metastases is unlikely to lead to wholesale changes in clinical practice, but may spur new studies into the role of local delivery of triple combination chemotherapy in these patients.

A randomised study of intravenous chemotherapy with 5-fluorouracil and leucovorin (folinic acid [FA]) versus prolonged hepatic arterial infusion (HAI) of fluorodeoxyuridine in patients with unresectable hepatic metastases from colorectal cancer (see opposite) has shown significantly improved overall survival, response rates and time to hepatic progression for fluorodeoxyuridine HAI, although time to extrahepatic progression was significantly shorter. Are these data sufficiently compelling for us to consider fluorodeoxyuridine HAI a new standard therapy for chemotherapy-naive patients with hepatic metastases?

The pharmacokinetic principles underpinning fluorodeoxyuridine HAI and 5-fluorouracil are compelling, as first-pass arterial extraction following HAI delivers a large fraction (60–80% of the delivered dose) of the cytotoxic agent directly to the liver. Given the steep dose-response curves and narrow therapeutic windows associated with these agents, significantly enhanced cytotoxic drug delivery results in higher intratumoural drug concentrations and higher consequent tumour-cell kill.

There are a few interpretative problems with the current study: the trial is rather small, especially for the marker component of the study; it is not a true comparison of the contribution of hepatic arterial delivery of chemotherapy, because the cytotoxic agents and the schedules for the two arms of the study are different; and it is possible that a degree of patient selection operated across the trial, as implied by the surprisingly long median duration of survival for patients receiving bolus 5-fluorouracil/FA.

Other well-designed trials comparing HAI and intravenous chemotherapy in this setting have not shown survival benefits for regional drug delivery.

The largest such study[1] randomised patients to identical 5-fluorouracil/FA regimens administered via the hepatic artery or intravenously. The use of ports rather than pumps in this study may have contributed to a higher technical failure rate in the HAI arm and therefore to the null effect.

It could be argued that HAI is technically cumbersome and expensive, requires a laparotomy, and has been bypassed by innovations in the management of hepatic metastatic colorectal cancer such as intravenous combination chemotherapy with irinotecan and oxaliplatin, the anti-angiogenic agent bevacizumab[2] and the anti-EGFR antibody cetuximab. Review of sequential clinical trial data from patients with advanced colorectal

---

*David Kerr is Professor of Clinical Pharmacology and Cancer Therapeutics and Director of the National Translational Research Network in the Department of Clinical Pharmacology at the Radcliffe Infirmary, Oxford, UK. This article was first published in *Nature Clinical Practice Oncology* 2006 vol. 3 no. 9, and is reproduced with permission www.nature.com/clinicalpractice, doi:10.1038/ncponc0566, ©2006 Nature Publishing Group

cancer suggests that median survival has risen over the past two decades from around 6 months to 24 months with modern systemic chemotherapy.[3]

On balance, however, the results of Kemeny et al. seem a timely reminder that we should adapt HAI to embrace advances in systemic chemotherapy.

Ongoing trials are exploring HAI of oxaliplatin[4] in combination with regional or systemic infusional 5-fluorouracil and bevacizumab or cetuximab.

Given the differential extrahepatic progression rate seen in the current study, a number of these studies are likely to unite regional and systemic treatment, but it could well be possible to administer drugs that are not limited by hepatobiliary toxicity via the hepatic artery in order to saturate the liver, and allow 'spillover' to generate equivalent venous concentrations, toxicity and pharmacokinetic properties to conventional intravenous schedules.

It is extremely unlikely that HAI fluorodeoxyuridine will be adopted wholesale as a novel frontline therapy for hepatic metastatic colorectal cancer, but this paper will serve as an important spur for the relevant phase II triple combination studies to be initiated using HAI chemotherapy.

Details of the references cited in this article can be accessed at www.cancerworld.org/cancerworld

Synopsis

N Kemeny, D Niedzwiecki, DR Hollis, et al. (2006) **Hepatic arterial infusion versus systemic therapy for hepatic metastases from colorectal cancer: a randomized trial of efficacy, quality of life, and molecular markers (CALGB 9481).** *J Clin Oncol 24:1395–1403*

Background. Metastasis to the liver occurs in approximately 60% of patients with metastatic colorectal cancer, and most patients with these liver tumours eventually die of their disease. Whereas the blood supply for normal liver parenchyma is via the portal vein, hepatic metastases receive most of their blood supply from the hepatic artery, so interest has been focused on the use of hepatic arterial infusion (HAI) for administering chemotherapy.

Objective. To assess whether HAI extends survival and improves tumour response and quality of life in patients with colorectal cancer that has spread to the liver.

Design and intervention. In this cooperative group trial, between 15 January 1996 and 29 December 2000, nine sites randomly assigned patients to receive either HAI with fluorodeoxyuridine, leucovorin (folinic acid [FA]) and dexamethasone or systemic chemotherapy with intravenous infusion of fluorouracil and FA. Resection of the primary tumour had been performed 3–4 weeks previously. No crossover between the study arms was permitted. All patients had histologically confirmed colorectal carcinoma with unresectable liver metastases over less than 70% of the liver parenchyma, and no extrahepatic disease on radiology. Patients with a previous or concurrent malignancy or impaired haematological or renal function were excluded.

Outcome measures. The primary endpoint was overall survival; toxicity, tumour response and quality of life were also evaluated.

Results. Patients receiving HAI (n=68) lived longer than those receiving systemic chemotherapy (n=67), with a median overall survival of 24.4 versus 20 months (P=0.0034). In comparison with the systemic chemotherapy group, patients receiving HAI had superior response rates (47% vs 24%; P=0.012) and longer time to disease progression in the liver (9.8 months vs 7.3 months; P=0.034), but shorter time to extrahepatic progression (7.7 vs 14.8 months; P=0.029). Diarrhoea, neutropaenia, and stomatitis were more frequent in the systemic chemotherapy group than the HAI group. Bilirubin elevation occurred in 18.6% of patients receiving HAI, but this was temporary in most cases. Improved physical functioning was observed in the HAI group at the three-month and six-month quality-of-life follow-up evaluations. For both methods of treatment, women fared better than men. Median survival was 29.4 and 22 months, respectively, for women and men in the HAI group, and 20.1 and 18.3 months, respectively, for women and men receiving systemic therapy (interaction P=0.016). A greater proportion of men than women receiving HAI had biliary toxicity (37% and 15% respectively; P=0.05).

Conclusions. HAI provides superior survival and better physical functioning than systemic therapy with the same agents for patients with metastasis of colorectal cancer to the liver.

Acknowledgement: The synopsis was written by Petra Roberts, Associate Editor, *Nature Clinical Practice*

Should patients with ovarian cancer receive intraperitoneal chemotherapy following initial cytoreductive surgery?

➜ Carolyn Runowicz*

A novel intraperitoneal chemotherapy regimen, trialled in the GOG 172 study, represents a new standard of care for patients with optimally resected stage III ovarian cancer, but should be offered on an individualised basis.

Interest in the intraperitoneal delivery of chemotherapy to patients with ovarian cancer with minimal residual disease following initial cytoreductive surgery has been rekindled with the recent publication of a Gynecologic Oncology Group study, GOG 172. This study compared intravenous paclitaxel followed by intraperitoneal cisplatin and paclitaxel, or by intravenous cisplatin, in patients with stage III epithelial ovarian cancer (optimal cytoreduction). The authors reported a 15.9-month improvement in median overall survival in those patients who received intraperitoneal therapy. The National Cancer Institute (NCI) issued a bulletin suggesting that, in women with stage III epithelial ovarian cancer, consideration should be given to the administration of intraperitoneal cisplatin and a taxane.[1]

This study and two previous randomised trials demonstrated an improvement in overall survival with intraperitoneal cisplatin. Alberts et al.[2] performed a direct head-to-head comparison, whereas Markman et al.[3] added two additional cycles of high-dose carboplatin in the intraperitoneal arm. Although the prior studies did not result in an NCI alert or a change in clinical practice, the data in aggregate warrant consideration of first-line intraperitoneal therapy in this group of patients. Before one adopts the current regimen, several issues deserve consideration.

GOG 172 compares three drugs (two intraperitoneal and one intravenous) with two intravenously administered drugs and a different schedule. The intraperitoneal route results in a continuous infusion via the intraperitoneal and intravenous route. Only 42% of the intraperitoneal arm received the assigned intraperitoneal therapy, and 18% of patients assigned to intraperitoneal therapy received intravenous carboplatin and paclitaxel after discontinuation of intraperitoneal therapy because of toxicity. Toxicities resulting in discontinuation of the intraperitoneal therapy included problems related to the access device, abdominal pain with infusion, and intolerance to the higher doses of cisplatin. How the number of cycles of treatment affected survival is unknown.

When GOG 172 was designed, the results of GOG 158 were not available. GOG 158 reported an improvement in median overall survival of 8.7 months (relative risk 0.84; 95% CI 0.70–1.02) for patients treated with intravenous carboplatin and paclitaxel compared with those treated with intravenous cisplatin and paclitaxel.[4] Although cross-trial comparisons are not statistically valid and the populations may differ, it is interesting to compare the differences in

---

*Carolyn Runowicz is Director of the Neag Comprehensive Cancer Center at the University of Connecticut Health Center, Farmington, Connecticut, USA

This article was first published in *Nature Clinical Practice Oncology* 2006 vol. 3 no. 8, and is reproduced with permission.
www.nature.com/clinicalpractice, doi:10.1038/ncponc0556, ©2006 Nature Publishing Group

outcome between the GOG 158 intravenous carboplatin plus paclitaxel arm and the GOG 172 intraperitoneal therapy arm. The difference in progression-free survival is 3.1 months and in overall survival 8.2 months between the two studies in favour of the intraperitoneal route. There are no differences in two-year survival rates, and only a 4–5% difference in four-year survival rates.

The results of this study and the previous phase III randomised trials[2,3] suggest that a new standard of care in chemotherapy has been reached in the primary chemotherapeutic management of small-volume residual advanced ovarian cancer; however, there remain a few hurdles to widespread acceptance. Until well-controlled, prospective randomised trials demonstrate a survival advantage over standard chemotherapy (intravenous carboplatin and paclitaxel, instead of intravenous cisplatin and paclitaxel, the control arm in GOG 172), intraperitoneal therapy need not be routinely administered to patients with optimal stage III disease. What practitioners should not do is make modifications to the regimen as published, as this might also modify the treatment's efficacy.

Details of the references cited in this article can be accessed at www.cancerworld.org/cancerworld

Synopsis

DK Armstrong, B Bundy, L Wenzel, et al. (2006) **Intraperitoneal cisplatin and paclitaxel in ovarian cancer.** *N Engl J Med* 354:34–43

Background. Surgery and standard intravenous chemotherapy with a platinum-taxane combination induces complete remission in the majority of patients with newly diagnosed ovarian cancer. Most patients will eventually relapse and die from their disease, however, despite escalation of the dose of intravenous chemotherapy. Although preclinical, clinical and pharmacokinetic data support the use of intraperitoneal therapy in ovarian cancer, this strategy has not been widely accepted.

Objective. To explore whether the use of intraperitoneal chemotherapy with cisplatin and paclitaxel improves progression-free and overall survival compared with intravenous cisplatin and paclitaxel in ovarian cancer.

Design. In this randomised, phase III study conducted by the Gynecologic Oncology Group, patients with stage III epithelial ovarian or peritoneal carcinoma who had not undergone previous chemotherapy or radiation were studied. Inclusion criteria were Gynecologic Oncology Group performance status 0–2 (where 0 was fully active and 4 completely disabled), residual mass following surgery limited to 1 cm in diameter, adequate hepatic and renal function, and normal blood counts.

Intervention. Between March 1998 and January 2001, participants were randomly assigned to receive six cycles of treatment with intravenous paclitaxel (135 mg/m^2) on day 1 followed by intravenous cisplatin (75 mg/m^2) on day 2 (intravenous therapy), or six cycles of intravenous paclitaxel (135 mg/m^2) on day 1 followed by intraperitoneal cisplatin (100 mg/m^2) on day 2 and intraperitoneal paclitaxel (60 mg/m^2) on day 8 (intraperitoneal therapy).

Outcome measures. Progression-free survival and overall survival were the primary endpoints, and toxicity and quality of life were also assessed.

Results. Median progression-free survival was 18.3 months in the intravenous therapy group and 23.8 months in the intraperitoneal therapy group (P=0.05). Median overall survival was 49.7 months in the intravenous therapy group and 65.6 months in the intraperitoneal therapy group (P=0.03). Compared with the intravenous therapy group, fewer patients in the intraperitoneal therapy group received all six cycles of the assigned treatment (42% vs 83%), and more patients had severe or life-threatening pain, fatigue or haematologic, metabolic, gastrointestinal, or neurologic toxicity (P<0.001). Catheter-related complications comprised the main reason for discontinuation of intraperitoneal treatment. After adjustment for baseline quality-of-life score, age and performance status, patients receiving intraperitoneal therapy had inferior quality of life before cycle 4 (P<0.001) and 3-6 weeks after treatment compared with patients receiving intravenous therapy, but there was no difference 1 year after treatment. Median duration of follow-up was 48.2 months in the intravenous therapy group and 52.6 months in the intraperitoneal therapy group.

Conclusion. Women with optimally debulked ovarian cancer receiving intraperitoneal therapy with cisplatin and paclitaxel following intravenous therapy with paclitaxel had a substantial reduction in the risk of death compared with women receiving intravenous paclitaxel plus cisplatin.

Acknowledgement: The synopsis was written by Petra Roberts, Associate Editor, *Nature Clinical Practice*

NEWSROUND

Selected press reports compiled by the ESO Cancer Media Centre

Culturally appropriate materials increase cancer screening rates

➜ Cancer

A recent randomised trial has found that low-income Chinese-speaking patients in America were six-times more likely to be screened for colorectal cancer when a clinic-based, multilingual health educator provided culturally appropriate counselling and educational materials.

Until a few decades ago, colorectal cancer was predominantly a Western disease affecting Caucasians. Studies of immigrants to the US from low-incidence countries show that colorectal cancer incidence increases within just one generation. In Hawaii and Los Angeles, colorectal cancer incidence rates among Japanese Americans are among the highest in the world. Moreover, these patients are likely to present with more advanced disease.

When detected at an early stage, colorectal cancer patients have an excellent prognosis, yet in America screening rates are low, with just over 50% of the eligible population having had a recent test.

Researchers investigated whether a clinic-based, multilingual intervention could increase uptake of colorectal cancer screening by faecal occult blood test among low-income, poorly integrated Chinese in America. One group received standard care and the other group received counselling from a trilingual and bicultural health educator and were given multilingual videos, pamphlets and test instructions.

Within the six months of the intervention, seven out of ten people (69.5 %) in the intervention arm had completed faecal occult blood test screening compared to fewer than three out of ten (27.6 %) in the control arm.

"Our results confirm the notable effectiveness of a multi-component, culturally appropriate health education program to promote faecal occult blood test screening within an ethnic minority group," the authors write. "The large effect of our intervention suggests the remarkable impact of culturally appropriate health education among populations with limited health information," they conclude.

■ Promoting culturally appropriate colorectal cancer screening through a health educator: a randomized controlled trial. S-P Tu, V Taylor, Y Yasui, et al. *Cancer* 1 September, 107:959–966

Tailoring treatment to disease severity can improve medulloblastoma survival rates

➜ Lancet Oncology

Radiotherapy that is adapted to the severity of disease and followed by a shortened course of chemotherapy substantially improves the survival of children with medulloblastoma, claim investigators in a recently published study.

Amar Gajjar, from St Jude's Children's Research Hospital in Memphis, Tennessee, said, "Not only can we now cure about 70% of children with high-risk medulloblastoma, we can also cure more than 80% of those with standard-risk disease, with a shorter, and therefore more convenient, chemotherapy approach". Using the standard therapy, children with high-risk medulloblastoma have a 30–40% chance of surviving to five years, and chemotherapy usually lasts for about 12 months.

In their study, the researchers adjusted the doses of radiotherapy given to 134 children with medulloblastoma, according to how severe their disease was. Children were classified as being either at standard risk, if they had only small tumours remaining after surgery and no evidence that the disease had spread to the rest of the body, or at high risk if they had larger tumours, or evidence of spread to other organs. Children in the high-risk group were given a higher dose of radiotherapy to the neck and spine than those in the standard-risk group. However both groups received an additional boost of radiation to the actual site of the tumour, a shortened course of chemotherapy, and a reinfusion of bone-marrow stem cells after each cycle of chemotherapy.

The children's survival rate increased to around 70%. Furthermore, Gajjar explains, "by reducing the amount of cisplatin from eight doses to four doses, and the amount of vincristine from 32 doses to just eight doses, we could alleviate a lot of the neurotoxicity associated with the higher dose of vincristine, without reducing survival."

Gajjar predicts that these findings could be the start of some exciting advances in brain cancer. "Our research focused on understanding the biology of medulloblastoma," he said. "We now need to develop a biological system of staging that works in conjunction with the current clinical staging system to further refine treatment for this disease." Until then, he advises, "investigators should consider adopting a similar therapeutic strategy to ours for their high-risk patients. This approach should be feasible in most paediatric oncology units at academic medical centres, but meticulous staging and careful attention to detail during radiotherapy planning and treatment are essential to obtaining similar outcomes."

■ Risk-adapted craniospinal radiotherapy followed by high-dose chemotherapy and stem-cell rescue in children with newly diagnosed medulloblastoma (St Jude Medulloblastoma-96): long-term results from a prospective, multicentre trial. A Gajjar, M Chintagumpala, D Ashley, et al. *Lancet Oncology*, published online 7 September, doi:10.1016/S1470-2045(06)70867-1

Exercise may improve colorectal cancer outcomes

➜ **Journal of Clinical Oncology**

Two separate studies have found that physical activity after patients are diagnosed with colorectal cancer may have a protective effect. The studies found that the risk of colorectal cancer recurrence and overall mortality decreased by around 55% among patients who did more physical activity, compared to those who were not physically active.

Both studies saw an improved prognosis with four to five 30-minute sessions of brisk walking a week, which is equal to 9 metabolic-equivalent-task (MET) hours per week. However, to see significant benefits, the length of walking time had to be doubled, or the intensity of the work-out had to be significantly increased (to 18 MET hours per week). Fitness levels before diagnosis did not appear to affect mortality.

In previous studies, exercise has been shown to have a preventive effect on breast cancer recurrence and mortality. Further research is needed to explore exercise and cancer and to examine the safety aspects of exercise for patients more prone to heart disease.

■ Physical activity and survival after colorectal cancer diagnosis. JA Meyerhardt, EL Giovannucci, MD Holmes, et al; Impact of physical activity on cancer recurrence and survival in patients with stage III colon cancer: findings from CALGB 89803. JA Meyerhardt, D Heseltine, D Niedzwiecki, et al; Cancer survival: time to get moving? [editorial]. W Demark-Wahnefried. *J Clin Oncol* 1 August, 24:3527–34; 3535–41; 3517–18

Many lower-risk prostate cancer patients may be overtreated

➜ **JNCI**

More than half of men with lower-risk prostate cancer received surgery or radiation treatment when a wait-and-see approach of no therapy and active surveillance would have been a reasonable option, according to a new study from the University of Michigan Comprehensive Cancer Center.

Research has shown that older men with lower-risk prostate cancer who choose so-called watchful waiting are likely to die from another cause during the first 20 years after their cancer diagnosis. Meanwhile, surgery or radiation to treat prostate cancer can lead to complications such as erectile dysfunction, urinary incontinence and bowel difficulties.

Researchers looked at 64,112 men diagnosed with early-stage prostate cancer. Men were divided into high-risk or low-risk categories, based on characteristics of their tumours. Among the 24,835 men with lower-risk cancers, 55% percent were treated with initial surgery or radiation, suggesting that aggressive treatment is quite common even among men where an expectant approach is a viable option.

The researchers found that, among men with lower-risk cancers, those under age 55 are more likely to be treated with surgery versus watchful waiting. In contrast, men aged 70–74 were more likely to be treated with radiation over watchful waiting. From 2000 through 2002, more than 13,000 men with lower-risk cancer received treatment with surgery or radiation within the first several months after diagnosis.

"Based on data from this study, it is clear that the number of lower-risk patients who receive initial aggressive therapy is not trivial and we have to ask the question whether this is too much treatment for some of these men," says lead study author David Miller. "We should continue to explore our patients' preferences regarding the different treatments for early-stage prostate cancer and better educate them about the entire spectrum of options, including the appropriateness of initial active surveillance in many lower-risk cases."

■ Incidence of initial local therapy among men with lower-risk prostate cancer in the United States. DC Miller, SB Gruber, BK Hollenbeck. *J Natl Cancer Inst* 16 August, 98:1134–1141

Obesity leads to more aggressive ovarian cancer

➜ **Cancer**

A new study provides evidence that obesity leads to more aggressive types of ovarian cancer. Researchers found significant differences in types of epithelial ovarian cancer depending on body mass index (BMI). In women with advanced disease, a higher BMI was also associated with decreasing survival rates.

Increasing evidence points to the importance of obesity (BMI >30) and being overweight (BMI 25–30) in the development and outcome of several cancers, including cancers of the breast, uterus and bowel. The relationship between obesity and ovarian cancer is not as clearly understood.

Almost 1 in 60 women will develop ovarian cancer during their lifetime. Most will be diagnosed with advanced disease, and 70% will die within five years, making it one of the most lethal cancers.

There are several types of ovarian cancer, but tumours that begin from surface cells of the ovary (epithelial cells) are the most common.

Andrew Li of the Cedars-Sinai Medical Center and colleagues reviewed data relating to 216 women with ovarian cancer to identify relationships between obesity, ovarian cancer, tumour biology and outcome.

Comparison of obese with ideal-weight women showed that 29% of obese women and 10% of ideal-weight women had localised disease. However, obesity was significantly associated both with different cellular characteristics of the tumour and with outcome in women with advanced disease.

Obese women were more likely to have mucinous types of tumours and tended to have non-serous types as well.

Though increasing BMI was not associated with differences in treatment for women with advanced disease, a BMI greater than 25 was associated with shorter disease-free survival. Increasing BMI was associated almost linearly with increasing risk of mortality.

"This study supports the hypothesis that obesity impacts ovarian cancer mortality by influencing tumour biology," conclude the authors.

■ Effect of obesity on survival in epithelial ovarian cancer. JC Pavelka, RS Brown, BY Karlan, et al. *Cancer*, published online, 28 August, doi: 10.1002/cncr.22194

Gene linked to colorectal cancer also implicated in cancer of the prostate

➜ Journal of Clinical Oncology

Important new information has emerged from the largest group of colorectal cancer families ever studied. The German HNPCC Consortium studied 574 families with a form of hereditary colorectal cancer called Lynch Syndrome. Two genes, MLH1 and MSH2, are implicated in this disease, and help to cause cancers by failing to repair defects in DNA which are cropping up all the time in normal wear and tear of the body's cells. The cancers are not associated with polyps, thus the acronym HNPCC, which stands for hereditary non-polyposis colorectal cancer.

The researchers focussed on tumour material from 1,381 cancers identified in a total of 988 patients from all over Germany. Definite or assumed mutations in the gene MLH1 were found in the tumours of 181 and 254 patients, respectively, and in the gene MSH2 in 259 and 294 patients, respectively.

Patients with the MLH1 mutations were younger when their first tumour was diagnosed and when the first colorectal cancer was picked up. Rectal cancer and cancer of the stomach were diagnosed very frequently in patients with either mutation. Several patients developed prostate cancers, all of whom had MSH2 mutations in the original cancer specimen. The time between first and subsequent cancers was shorter in patients whose cancer was on the left side of the colon.

The authors recommend a redefinition of treatment strategy for rectal cancers, regular surveillance of the stomach and earlier colonoscopy, especially in males, probably starting as early as 20 years of age. The link to prostate cancer in MSH2 mutation carriers needs to be borne in mind in the follow-up of these families in the genetics or oncology clinic.

■ Genotype-phenotype comparison of German *MLH1* and *MSH2* mutation carriers clinically affected with Lynch Syndrome: A report by the German HNPCC consortium. T Goecke, K Schulmann, C Engel, et al. *J Clin Oncol* 10 September, 24:4285–92

Genetic testing may predict if lung cancer will return

➜ New England Journal of Medicine

A recently published study has shown that genetic testing can help identify aggressive, early-stage, non-small-cell lung cancer.

Currently patients with early non-small-cell lung cancer, identified as stage IA, are not given chemotherapy after surgery, as clinical trials have indicated no benefit. However, in a quarter of these patients, the disease returns. Researchers from Duke University Medical Center, America, looked for a way of identifying at-risk patients.

Almost 130 patients with the disease took part in the study. The researchers found that they could accurately predict aggressive forms of lung cancer by scanning the patients' genes.

Many doctors believe the current staging system used to group lung cancer patients is no longer an accurate indicator of treatment. A genetic test now appears to be a more accurate way of deciding on treatment programmes for non-small-cell lung cancer patients with stage IA disease.

Further clinical trials are due to take place in America and Canada involving 12,000 cancer patients.

■ A genomic strategy to refine prognosis in early-stage non-small-cell lung cancer. A Potti, S Mukherjee, R Petersen, et al. *New Engl J Med* 10 August, 355:570-580

What's brave about having cancer?

Riazat Butt

On September 1st, exactly six years after being told she had only six months to live, Jane Tomlinson completed a gruelling 6,780-km bike trek across America. Before setting out, she talked about why she refuses to sit at home waiting to die.

Jane, 42, looks like a frazzled housewife. She doesn't look like someone who does Iron Man competitions – a 4-km (2-mile) swim followed by a 180-km (110-mile) bike ride and a full marathon. Some days, she can't take the laundry downstairs. Mike, 45, remarks how people always think Jane is bigger than she is. She's 5ft 3in (1.6 m).

In 1990, Jane was diagnosed with breast cancer. In the decade that followed she had a mastectomy and underwent two seemingly successful rounds of chemotherapy and radiotherapy. Then, in 2000, she learned the cancer had spread to her bones. It was incurable and the prognosis was that she had six months to live. In the past six years, Jane has had a total of five courses of chemotherapy and has just finished a course of the breast cancer drug Herceptin.

Perching on the edge of the sofa, Jane says that she hasn't been well. Her fatigue, just before departing for the US, is worrying. Today she begins a 4,214-mile [6,780-km] bike ride from San Francisco to New York. Even judged by her previous accomplishments – four marathons, three triathlons and a cycle ride from Rome to Leeds – it's a challenge.

"It's the scale that's making me nervous," she says. "It's what we're doing for nine weeks. It's the sick feeling you get; it's about having said I'll do it. I feel I'm putting myself out there maybe for people to watch me fail."

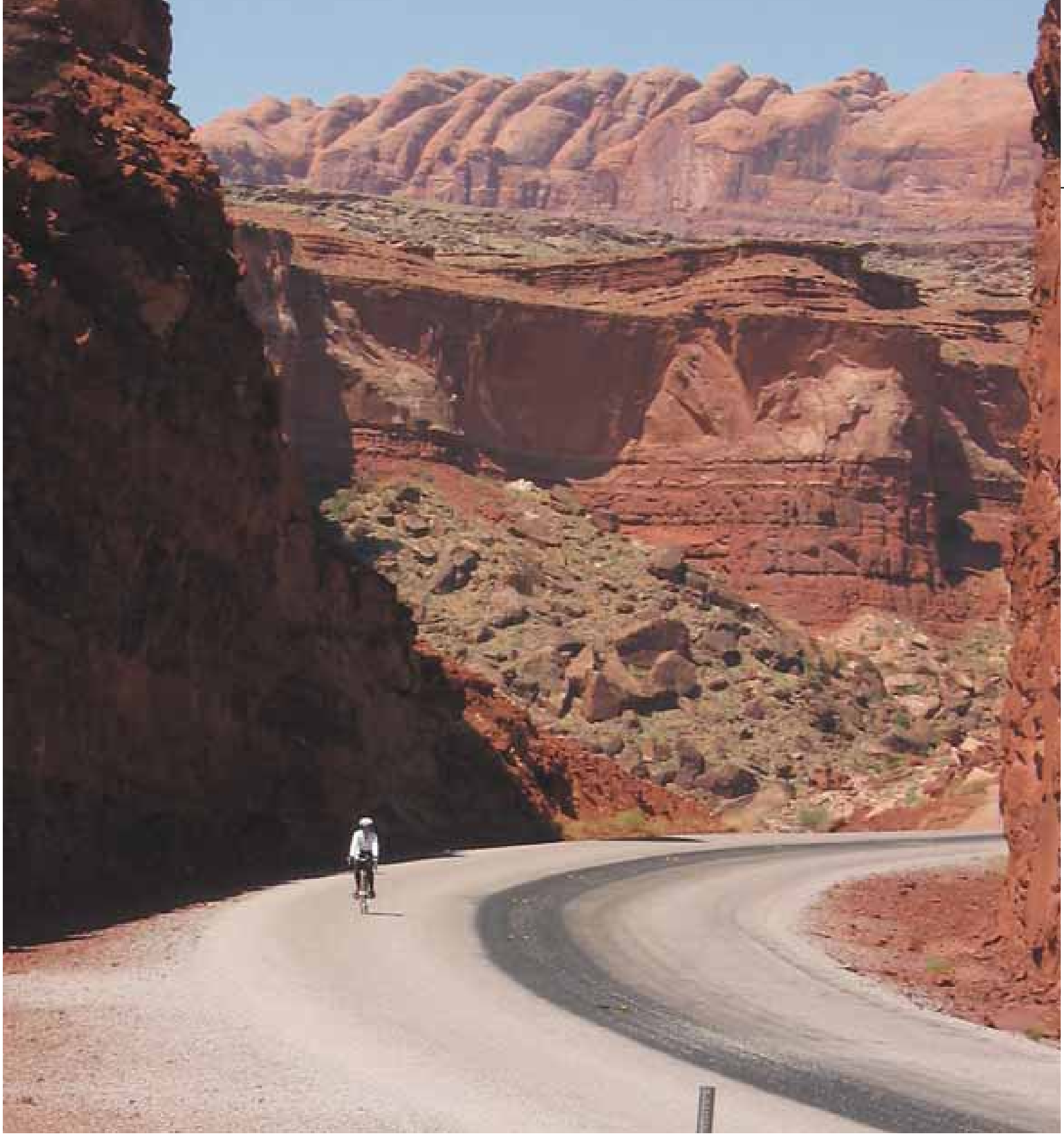
The epic coast-to-coast journey has been 15 months in the planning and was dependent on Jane having a base level of fitness she could work from. "I'm not going into this thinking it will be a breeze. I'm quite frightened. I don't know the terrain. Some of the temperatures will be extreme – I mean, cycling in 45°C [113°F] is ludicrous. It's done on a wing and a prayer."

On this trip, she will be joined by Mike, Steven and daughter Rebecca, 18 – her eldest daughter, Suzanne, is at university. "It doesn't make it easier having Mike and Steven there, but I don't want to be away from them for that amount of time. We'll have collective memories and shared experiences – though I can imagine getting off my bike after a 70-mile day and Mike asking what we're having for tea."

The purpose of the trip is to raise money. Her gruelling endeavours have so far made £1.25m (1.86m euro) for cancer charities, and she is hoping the cycle ride will take this to £2m. "We don't seek publicity," she says. "Some glossy magazines want to do an 'at home with' feature. But have you seen the state of this place?" Her dry self-deprecation is tempered with flashes of steel. While her endurance achievements have earned her the affection and respect of strangers, she has also been criticised for the amount of time she spends away from home. But, as she explains in her matter-of-fact way, the challenges give her goals to plan for that are not too painful to contemplate falling short of. She would like, she says, to see Rebecca through university, and would like to see Steven into secondary school – but that's an emotional investment. She never thought she would live to see Suzanne reach her 21st birthday. "If I had been really poorly and died, it wouldn't have mattered to me because I'd be dead, but it would have brought extra disappointment [to the family]."

Concerns have also been raised about the danger of setting standards by which other people with cancer will be judged. She is, she says bluntly, the most reluctant of role models: "Cancer sufferer – those two words narrow my life. As if there's nothing else to my life. Cancer is a bit of my life.

"I'm here six years after I expected to be here. People tell me I'm selfish, that I should sit at home. It's like your



Pedal power. Tomlinson is not going to let her life be defined by the words 'cancer sufferer'

The challenges give her goals to plan for that are not too painful to contemplate falling short of

life has no validity unless it's for someone else's memory. It's insulting. When you're poorly, you can't do the housework, you can't do the cooking, you can't do your job. To say that you should sit in the corner so people can visit you – it's like living your own wake. It makes me a bit angry."

She laughs at the suggestion that she's stroppy, but she also seems pleased by the notion. If she has become a mascot for triumph in the face of adversity through her charity work, proving that chemotherapy and radiotherapy needn't entirely ruin someone's quality of life, that, she says, is a by-product, not something she set out to achieve.

"I am a mother, a sister, a daughter, a wife. And I happen to be a cancer sufferer. Why do I even have to be a sufferer? And what's brave about having cancer? Living with cancer isn't courageous. You make the choices you can in difficult circumstances. It's just having a shitty life. It's shit having cancer."

And the treatment that has helped to keep her alive is a double-edged sword: "I've had two rounds of chemotherapy in two years and it's bloody horrible. Nobody tells you that. Nobody writes about how awful you feel after chemo. People see your hair fall out, but that's not the worst of it. I can't feel the fingers in one

The last leg.
Passing the White House
en route to New York

> "Living with cancer isn't courageous. You make the choices you can in difficult circumstances"

hand. I can't feel the balls of my foot, which makes cycling difficult. My mouth is sore. Your diarrhoea is so bad you're pooing blood."

Listening to Jane, you begin to see how the rigours of cycling up to 90 miles a day in blistering heat might almost be a welcome distraction; something else to worry about, a different sort of pain. "You go through the treatment and, six months later, you go through it again. You do it because you know that's the only way you're going to be around for your family."

And then it's time for her to get to hospital. The needles are waiting

---

This article was first published in the *Guardian* newspaper on 29 June 2006, and is reproduced with permission

THE CHALLENGE

Jane's Ride Across America would have been an extraordinary feat of endurance even if she were perfectly healthy. It started at the Golden Gate Bridge in San Francisco on the 30th June and ended in New York 62 days and 6,780 kilometres later, on 1st September. Her route took her across the Sierra Nevada, the Rocky Mountains and the Appalachians and included a 200-km stretch that never dipped below 2,100 metres, rising to almost 3,500 metres as she crossed Monarch Pass. The Tour de France never rises above 2,000 metres.

With minimal back-up and two companion cyclists, Jane travelled some of the most deserted stretches of road in America, relying on maps that sometimes let her down, and having on several occasions to fend off attacks by packs of wild dogs. You can read a blog of her journey at www.Janesappeal.com or www.thesun.co.uk/blogs.

To donate to Jane's Appeal log on to http://Janesappeal.com or call +44 (0)845 1200829