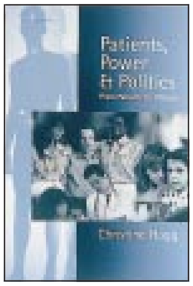
reviews

BOOKS • CD ROMS • WEBSITES • MEDIA • PERSONAL VIEWS • SOUNDINGS • MINERVA

Patients, Power and Politics: From Patients to Citizens

Christine Hogg



Sage, £16.99, pp 219
ISBN 0 7619 5878 9

Rating: ★★★

For most of the time for most people, health services are not important, and yet, as Christine Hogg reminds us, "Everyone of us is at some time or another a patient." This fate is as inevitable as death and taxes, and, like their attitude to these other eternal verities, people often feel powerless when confronted by it.

In the 20 years that I have been involved with campaigning about healthcare issues I have continually had to struggle with the sheer complexity of the subject. Just understanding the plethora of trusts and authorities within the NHS, and the way they work together, can take years to grasp. Users wanting to get involved face a daunting task in trying to understand how the NHS works and who might be able to make what changes.

Similarly, I have met many healthcare professionals who, while confident within their own small domain, have little inkling about how the rest of the service works. They may also want to involve users, having recognised that this a good way of improving services, but then discover that the issues are not as they expected. What seems important to a doctor or a manager may not be so for the user. Most research on cancer is about the effects of chemotherapy on cancer cells, but women with breast cancer equally want research on the treatments' effects on quality of life.

Anything that helps us to understand the complexities of healthcare provision and what issues are important to users is therefore helpful. I welcome Christine Hogg's excellent summary of the issues raised by users about healthcare services. It clearly informs readers of the debates that need to take place and of the issues that healthcare practitioners should address in order to better serve their users.

However, one question kept cropping up in my mind—who will read this book and what will they do afterwards? According to the blurb on the back, it will be "invaluable reading for students and academics in health care, health ethics, health policy, planners and practitioners in health and social care, and voluntary organisations and user groups." That's an awful lot of people, but will they all find it useful? Only if they are prepared to go beyond what is presented and recognise that, having the issues so clearly delineated, it is time for them to start discussing these issues with users.

So read the book to gain a better understanding of some of the issues that users feel strongly about, but do not think that this is an end in itself. It is merely a starting point for discussions with users and user groups.

Stephanie Ellis *chair of Camden Community Health Council, London*

JOURNALS

Health Expectations

Blackwell Science, Annual subscription £180
ISSN 1369 6513

Rating: ★★★★

Health Expectations is a new journal, established in 1998 and published quarterly from 1999. It focuses on "things done *with* the active involvement of patients, users or citizens" rather than "things done *to* them." These include "involvement of patients and their advocates in decisions about individual health care; involvement of users and their representatives in service design, delivery, and evaluation; and involvement of consumer advocates and the general public in debates about health care."

The four issues published so far contained 16 research papers, seven "viewpoints" or literature reviews, and 25 reviews of books or resources in 219 pages. Most of the published research concerns the involvement of individual patients, focusing on information aids and patient satisfaction. The remaining research papers deal with surveys on users' opinions about specific topics that are relevant to health policy making. The viewpoints and literature reviews refer to debates about the organisation and delivery of health care, while the reviews cover books on user involvement and information aids for users and patients.

The format of the articles is similar to that in most medical journals, although the papers are somewhat longer than usual. Examples of the published research include a pilot study of an information aid for women with a family history of breast cancer, a survey of the use of evidence by healthcare user organisations, an in-depth analysis of shared decision making in consultations for upper respiratory tract infections, an interview study on the relation between expectations and satisfaction of patients who considered surgery for gynaecological cancer.

Health Expectations has certainly expanded the opportunities to read and publish articles on involvement of patients and users in health care. Concentrating such papers into one journal should make it much easier to learn about new developments in the subject, as such articles were previously scattered among many journals. *Health Expectations* may therefore stimulate further research and development in this subject. One limitation is that it is not very interactive: it does not yet have a section for letters to the editor or a website for responses to published papers. Another limitation, also mentioned by the editors, is that the journal has a strong British orientation.

A major danger is that the journal will become (or be regarded as) a promoter of involvement of patients and users as such. The editors are aware of this danger, as one of them writes in an editorial that "progress is hampered by the politically correct position that more participation is always a good thing." Furthermore, at least one of the papers reports on negative consequences of greater patient participation: patients who received more information on coronary angiography were less satisfied with the care they received. It is crucial that the editors maintain this critical and balanced approach.

I am not sure whether *Health Expectations* has a long term future. The interest in patients' and users' involvement in health care is currently fashionable, but that may disappear, and well designed studies in the subject may increasingly be published in established healthcare journals. In the meantime, however, *Health Expectations* should provide an important forum for research and debate on the subject.

Michel Wensing *research fellow, Centre for Quality of Care Research, Universities of Nijmegen and Maastricht, Netherlands*

NETLINES

- A quarter of all the material on the internet is health related (**www.ama-assn.org/sci-pubs/journals/archive/jama/vol_281/no_4/cv80008x.htm**). About a third of web surfers are searching for health information (**www.rcsed.ac.uk/journal/vol44_4/4440040.htm**). Much of this material is not technical but of interest to consumers.

- A comprehensive starting point is the Hardin Meta directory at **http://www.lib.uiowa.edu/hardin/md/index.html**, which is effectively a gateway to other directories. This site is catalogued by specialty, but it is more than just a simple (and extensive) collection. The webmaster has gone to the trouble of checking that the links within the target directories are functioning, and Hardin is quite choosy about whom it includes (see **www.lib.uiowa.edu/hardin/md/submit.html**). If you cannot find what you are looking for in Hardin, there is a list of other similar collections. This site allows the user to locate specific good quality information quickly.

- Another guide to appraising health information is an instrument called DISCERN (**www.discern.org.uk**). A questionnaire prompts assessment of the quality of health information materials. The instrument has been widely validated for written leaflets and for use by designers of new information as well as people assessing existing material.

- A site that caters for both doctors and patients is at **www.cancerbacup.org.uk**. This UK based resource on cancer information and support is aimed primarily at people with cancer and their families or carers; the home page proudly proclaims that there are about 1500 pages of data. It is a content-rich site, with the main button bar sporting separate sections for health professionals and patients. The division between the information needs of the health professional and those of the lay person becomes blurred when the information is presented well, as is the case with this website. But the addition of a site map would greatly help navigation.

- **www.betterhealth.com/virtualcheckup/noplugin/heart/index.html**, as the URL suggests, is a "virtual check up" and relies on consumers inputting data relating to their cardiovascular health, such as blood pressure and cholesterol concentration. The site then gives an assessment coupled with a diagram of the coronary arteries. "Bad" news from the self assessment may cause alarm—but others may feel that they must do something to improve their health. At least it is thought provoking and may promote a better lifestyle. As internet technology improves, we will certainly see more (and more sophisticated) variations on this kind of interactive consultation.

- To see some of the best design in a health website, visit Cancer Help UK (**http://medweb.bham.ac.uk/Cancerhelp/indexg.html**). Based at the University of Birmingham in the Cancer Research Campaign's Institute of Cancer Research, this site is unusual for its consideration of novice users. There are several ways of accessing information, which allows readers to choose how they drill down to the desired information. A glossary of terms can be left permanently on in a separate window, for looking up unfamiliar words. None of these touches is unique, but the combination is unusually friendly.

- Information on the web (or in newspapers and magazines) may not be all that it seems—hence the importance of critical appraisal skills. A site to teach this to children is Quick (**www.quick.org.uk/**), a quality information checklist for health. It is a crisp, speedy, entertaining, and well illustrated resource. Guidance for teachers is also available at **www.quick.org.uk/teachers.htm**.

- Currently being developed is the "building site" of the National Electronic Library for Health (**www.nelh.nhs.uk/buildng.htm**). The site takes its architectural theme a long way: when the library is built there will be a floor for patients (branded as NHS Direct online) and the whole enterprise will revolutionise information flows. Check the blueprints yourself.

- A branch of the US based National Institutes of Health has produced a publication on impotence for doctors and patients (**www.niddk.nih.gov/health/urolog/pubs/impotnce/impotnce.htm**). It is simply and clearly laid out. There are no links to other external impotence websites, but a major plus is the lack of copyright, allowing unlimited copying and dissemination of the contents of the page.

- After being diagnosed with a condition, patients may want to join a self help group or a support group, but often the problem is finding a suitable one. Two good UK sites that can help are **www.cafamily.org.uk/home.html** and **http://www.patient.co.uk**. A useful place to start hunting for US based self help groups is to look at **www.healthy.net/home/index.html**. This can lead to a massive archive of contacts within a few mouse clicks.

- And finally, point your browser at **http://pbcn.findhere.com** and read the welcome page from the Philippine Breast Cancer Network, a patient pressure group. The site contains moving stories of women and their battle with breast cancer; equally it emphasises the point that the internet is the number one global publishing medium.

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David Dickinson *consumer information designer, UK*
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We welcome suggestions for websites to be included in future Netlines. Readers should contact Harry Brown at the above email.

Struck off, but why?

The message to parents was clear: be afraid. Your family doctor may strike you and your children off the list without rhyme or reason.

The *Daily Mail* led the clarion call to arms on Wednesday, 8 September. Next to a picture of a cute blond child and his smiling mother, its large print opening paragraph accused doctors of "striking off children whose parents refuse to let them have the controversial MMR jab." On 13 September, the *Independent* told us that doctors were "striking from their lists huge numbers of patients, including children."

What could possibly drive GPs to such cruelty against the small and defenceless? Lucre of course. The *Express* headline on 13 September trumpeted its outrage at our "Greedy GPs' vaccine ploy" and called them "devious doctors." The *Daily Mail* announced none other than a full blown "MMR jabs cash scandal." You could almost picture the masked villains, stethoscopes around their necks, running from their surgeries with bags labelled "swag."

Like proud detectives unravelling a complex sting operation, all three papers educated their readers about the sordid details of this "trim and win" swindle. GPs were being given "large bonuses" (*Daily Mail*) for reaching percentage targets for immunisation and screening. To keep these figures high, doctors were removing "uncooperative" parents (the *Independent*) and "women refusing a smear test" (the *Express*) from their lists. Had doctors really been caught red handed? Where was the evidence?

The clues could apparently be found in an enigmatic paper called "The struck-off mystery," in September's *Journal of the Royal Society of Medicine* (1999;92:443-5). The paper was launched with a dramatic press release that talked of "millions of patients" being struck off each year.

Prompted by their observation during a psychiatric ward round that four out of six patients had been struck off since admission, Dr Neena Buntwal, a senior registrar in psychiatry, and her colleagues at the Bethlem and Royal Free Hospitals, audited 50 patients across their mental health unit. They found that 30% had been removed from their GP's register at some point and so formulated a hypothesis that "behavioural and psychiatric disorders were a common reason for being struck off."

Their sleuthing began with a direct appeal, through a local publicity campaign, to patients who had been struck off. The authors hoped to assess psychiatric illness in the members of this group and compare them with controls. Few patients came forward, and many GPs refused to display posters in their waiting rooms. Undeterred, the researchers approached two metropolitan family health authorities, asking them to send questionnaires to all patients who had been struck off their GP's list. One authority refused to cooperate without giving a reason and the other contacted the local medical committee which demanded that the study be stopped.

After lengthy negotiations, the authority agreed to cooperate provided that GPs were given a chance to explain their actions. Three years after agreeing, the newly restructured local health authority wrote to the authors "stating they had sufficient reservations about our study to decline the release of any further information." No data on reasons then. Unhelpful? Yes. Intriguing? Most definitely.

Raw data from the health authority show that there has been a three-fold increase in the number of patients removed from lists between 1994 and 1997. Assuming that the population has remained stable, this suggests an increase in the rate of removal, which clearly requires explanation. The authors proffer one version, and here, at last, the fingerprints almost match those of the tabloids: "If some patients are being struck off for economic reasons, this may be a reason why we have found it so difficult to carry out this research."

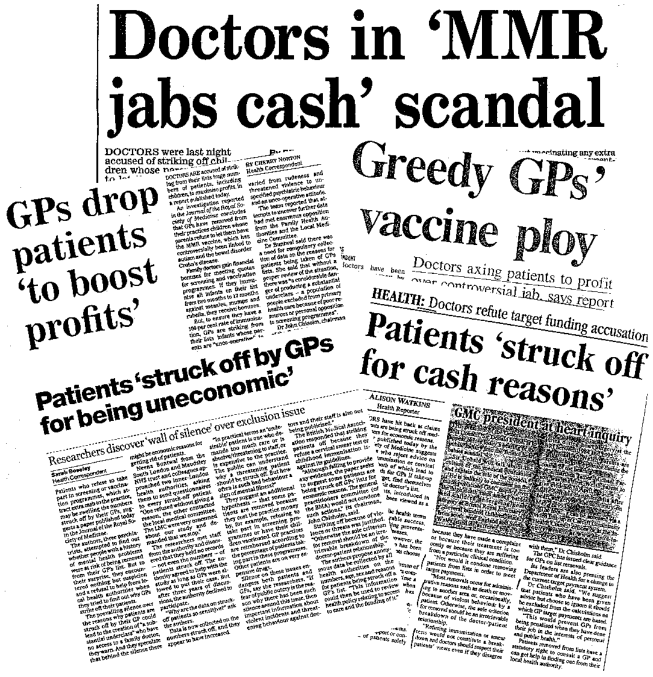
Deep within the discussion section lies the source of the media's panic. Patients on expensive atypical antipsychotic drugs could be financially unattractive to GPs, and there is at least one practice that "restricts its prescribing of antidepressants to tricyclics, openly for cost reasons." And finally we come to the dastardly deed itself: a single paragraph raises the possibility of monetary gain by removing parents who decline the MMR triple vaccine for their children.

The tabloid furore was graphically illustrated by liberal quotation from this paragraph. The *Daily Mail* quoted Dr Buntwal as saying, "I have heard some GPs are even taking children off their lists during the age range when they are due to be vaccinated and returning them later." Not a conclusion that could have been drawn from Dr Buntwal's study.

Dr John Chisholm, chairman of the BMA's General Practitioners Committee, tried to reassure the public. He criticised the psychiatrists for "failing to provide any evidence" for their allegations about doctors' behaviour and rejected the idea of "millions" of patients being struck off, offering a more sobering figure of "one or two removals per GP each year." Readers were reminded that "the sole criterion for removal should be an irretrievable breakdown of the doctor-patient relationship."

The true crime, of course, is that health authorities are not obliged to keep data on why patients are being taken off lists. As the authors of the study point out, there may indeed be "a considerable danger of producing a substantial underclass—a population of people excluded from primary health care because of poor resources or personal opposition to screening programmes." We will never know this without the compulsory collection of data. The lack of information makes for a dreary headline, as does talk of public health and policy. Instead the papers preyed on the anxieties of those who may already be vulnerable—parents worried about vaccination, patients with mental health problems, women who declined cervical smears. The struck off mystery remains just that: we still do not know why patients are being removed from GPs' lists.

Gavin Yamey *BMJ*



Doctors in 'MMR jabs cash' scandal

GPs drop patients 'to boost profits'

By CHERRY NORTON Health Correspondent

Greedy GPs' vaccine ploy

Doctors axing patients to profit over controversial jab, says report

HEALTH: Doctors refute target funding accusation

Patients 'struck off for cash reasons'

ALISON WATKINS Health Reporter

GMC president at heart inquiry

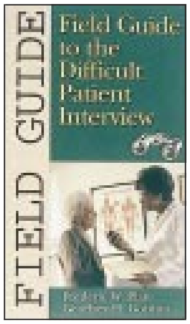
Patients 'struck off by GPs for being uneconomic'

Researchers discover 'wall of silence' over exclusion issue

Sarah Boseley Health Correspondent

Field Guide to the Difficult Patient Interview

Frederic W Platt, G H Gordon



Lippincott Williams and Wilkins, £17.95, pp 250
ISBN 0 7817 2044 3

Rating: ★★★★

There has been much research into communication between doctors and patients, and, for the most part, doctors come out of it badly. We're not very good at transmitting information, and we're no better at picking up the signals that patients try to send. Observers of doctor-patient transactions make the telling point that individual doctors display little variation in their approach to different patients.

Of course, this is familiar stuff. Excuses trip off the tongue easily enough. We are doctors, after all, not counsellors; we haven't enough time; we haven't been properly trained; and patients are unrealistic in their expectations of what modern medicine can do for them. But it's worth remembering the abundant evidence that better communication leads to greater patient satisfaction, closer adherence to prescribed treatments, improved clinical outcomes, and fewer law suits.

Good clinicians already spend time thinking about the way in which they listen and talk to their patients. They will certainly find this book helpful. It's short, attractively laid out, and easy to read. Better still, it avoids banalities. There are no futile exhortations to shun jargon or never to seem rushed. Best of all, it concentrates on specifics. It explains, for instance, how easy it is to behave in a way that that blocks communication—ducking issues that make one uncomfortable, failing to respond to a patient's distress signals, closing discussions prematurely, or not following up on ambiguous answers. Individual chapters cover many of the difficult situations that cause the medical heart to sink. Hostile patients, patients who bring lists, and patients with multiple somatic complaints are just a few of the problems dealt with.

The authors have hit on the idea of providing snippets of imaginary consulting room conversations to illustrate important points. This device works well, partly because it makes general principles concrete but also because it suggests forms of words and practical strategies that one might use oneself. If a book about communication can be judged by how well it communicates, this one is dazzlingly successful.

Christopher Martyn *BMJ*

PERSONAL VIEWS

Clowning in hospitals is no joke

The 28 members of Le Rire Médecin (Laughing Doctors) have worked closely with hospital medical staff in France since 1991. Twice a week the group holds specially conceived shows for children and their families in paediatric wards in eight hospitals—six in Paris. Each year it performs for more than 30 000 children, a similar number of parents, and more than 60 000 medical personnel.

The group fills a gap left by other hospital activities carried out by teachers and volunteer workers and provides a vital part of the effort to humanise the care of children.

The group fills a gap left by other hospital activities

To our knowledge the only other groups which perform a similar function are The Big Apple Circus Clown Unit in New York, the Doutores da Alegeria in Brazil, and Die Clownen Doctors in Germany.

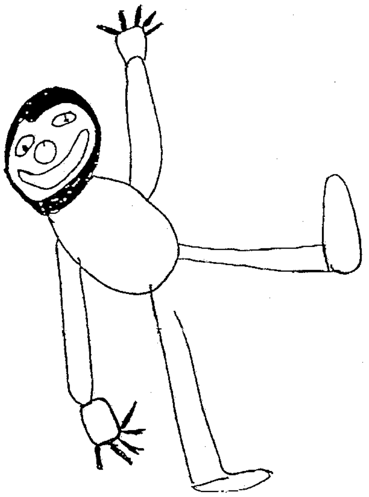
By 1993 we decided that with the emergence of other groups it was important to define the basic principles of our work and to create some rules for clowns performing in hospitals. Le Rire Médecin already had projects for training performers, but one of the dilemmas for artists working in a hospital is the question of confidentiality. Is it necessary for a clown to know if a child is in pain, has been molested, or has an incurable illness? Experience has taught us that to remain sensitive to each patient it is important for performers to modify their gestures or physical distance from a patient and even to question the choice of a song. We also need to have the trust of the medical team in order to work on a long term basis with their patients.

We studied other codes, numerous guides, and various sets of rules. Some we ignored, some inspired us, and some we transformed. We wanted a living document that could be modified by other groups of artists and adapted to other cultures. Would other groups bother to apply our principles? How could we control the quality of their work? How could we guide other artists working in hospitals to work honestly? We decided that we needed to define the difference between a "walk around" clown job, family entertainment, and in depth work interacting with a medical team.

The first draft of the code was draconian and the reaction to it was varied. Those who already practised under a professional code—physical therapists, nurses, and doctors—were reassured and at ease with our code. The others—clowns, administrators, and teachers—were worried that such a document would block the creative drive of artists and that it was following the obsession of being politically correct.

For example, in a paediatric ward with seriously ill children it is important that the usual creative process of an artist or clown should be respected while he or she is required to obey a few basic principles. There are 11 basic articles in Le Rire Médecin's code. They define standards of professionalism, boundaries of artistic expression, limits of the creative role, responsibility of each artistic act, respect for patients as well as health care workers, privacy, emotional parameters and distance from patients, basic safety, and even hygiene.

Most of the clowns who have worked with Le Rire Médecin for eight years think that the code has provided them with a framework which frees them to create. We hope to maintain a policy of professional discipline and honest craftsmanship. This requires frequent self evaluation and dialogue with the hospital staff. We would never have been able to accomplish the quality clowning that we have without the support and good will provided by the medical staff. They have given us our place in their world that traditionally provides little room for new disciplines.



After all, what a provocative job it is to be the funny one in such serious places as hospitals.

Caroline Simonds *founder and artistic director, Le Rire Médecin, Paris*
email: riremed@club-internet.fr

The clowns' code of ethics is available in French and English on the *BMJ*'s website www.bmj.com

Reviews are rated on a 4 star scale (4=excellent)

All change?

“But *why* do doctors have different opinions about what is the best treatment? There are thousands of people going through this every year—why don’t they know which works best?”

I try to explain to a member of my antenatal class who has called me for reassurance, something about the nature of medicine, about how little research there is in some areas, and how contradictory the results can be. But it’s not really what this patient wants. In a burst of honesty her doctor had the temerity to admit that variations in practice exist. Instead she wants a cut and dried answer because that is her expectation. Behind her are years of conditioning to believe that as medicine is a science it must produce hard facts and straightforward answers.

If only it were that easy we could just plug ourselves into a computer for a diagnosis and treatment printout. Clinical judgment would be redundant. But if patients wish to increase equality with doctors they too will need to face the uncertainty that doctors work with every day.

To share power, patients need to acknowledge that they deserve it

In my work as an antenatal teacher and patient supporter, both doctors and patients often expect me to take the patient’s side. Even if I agreed that there are sides to be adopted I find that sometimes I cannot support the perspective that doctors are always at fault. To achieve a more equal relationship patient attitude and behaviour will also need to adjust.

The drive towards patient choice and involvement in care is truly a double edged sword. When treatments work and patients feel that they have participated in achieving their own wellbeing I have seen it enhance their confidence and feelings of worth. But acquiring enough knowledge about their condition to make decisions can be a steep learning curve, and is simply unrealistic for some. And with rights comes responsibility—when treatment does not work they literally have no one to blame but themselves. Not everyone wants or can handle this responsibility.

To get the appropriate level of involvement for themselves patients should be clear about what sort of patient and doctor relationship they want. I cynically imagine a questionnaire for all new patients: “Please give me the whole truth; only the good news; just a prescription, thank you.”

Most complaints about doctors that my clients bring to me are not about the actual treatment, but about communication. But patients themselves are not always skilled communicators. A patient I was supporting recently had complained of a lot of pain. When the consultant arrived and inquired, “How are things?"—a perfect opening for all manner of complaints—the patient replied, “Fine, thank you.” By adopting a “mustn’t grumble” attitude this patient risked not getting the treatment she needed. Patients should feel able to state their symptoms in an assertive manner without worrying that they are whingeing or being difficult; otherwise they collude in their own powerlessness. To share power, patients need to acknowledge that they deserve it.

To relate to doctors in a more equal way patients will also need to change their ways of thinking about them. Media portrayal has a lot to answer for here. Virtually every page of any television guide contains the word “doctor.” The stereotype in medical dramas of the handsome, caring maverick, who breaks the rules to help his patients, who is emotionally caught up in every case, is simplistic and pervasive. This is worlds apart from the wholly appropriate level of detachment that facilitates rational decision making and prevents emotional burnout. Patients sometimes complain to me that doctors seem “uninvolved.” I often feel that they are demanding from doctors the sort of emotional support that would be far better given by a relative, friend, or fellow patient. They may need to be more realistic about what doctors can offer.

A lot of the debate on the changing relationship between patients and their doctors concentrates on the adjustments that doctors will have to make. It works on the extreme stereotypes of the “big bad” doctor versus the “poor downtrodden” patient. It is true that some doctors still do not recognise that both illness itself and treatment can be so detrimental to self image. I wish I could say that the “get a grip” attitude is a thing of the past. And I know that patients have, at cost to themselves, told personal stories of appalling treatment and put their pain on public view, to say, “This cannot go on.”

But there is a price to be paid for the gains they will make. If they really want equality patients are going to have to do some changing too. They must face uncertainty, take responsibility for decisions, and communicate clearly, all based on a realistic view of what doctors can offer. Are all patients prepared for that?

Ailsa Harrison *antenatal teacher and patient supporter, High Wycombe*

If you would like to submit a personal view please send no more than 850 words to the Editor, BMJ, BMA House, Tavistock Square, London WC1H 9JR or email **editor@bmj.com**

SOUNDINGS

On the beach

The shore is long and straight, narrow, and quite steep. The sea is calm. In the light that is left an hour after sunset a dark bulky shape stirs in the hollow that it has excavated in the dry sand above the high water mark. A female loggerhead turtle begins to lay her eggs.

Well over a metre long and almost a metre wide, she has come thousands of miles for this and will not be distracted. My son inches closer, engrossed by the strange creature, her size and shape, her generally prehistoric, even science fiction aspect: reptile head, flippers, shell, and tail, and the brisk matter of fact productivity of her prodigious egg laying.

Next morning she is gone, her nest covered over with dry sand, her track the only sign: the slow drag back to the water, the scrape from her belly, the clear claw marks from her propelling flippers on either side. On our morning walk along the beach there are dozens more such tracks, some as fresh, some older: windblown and obscured.

Conservationists are concerned. Pollution, including light pollution along the now populous barrier islands, are recent hazards to a pattern of animal life and behaviour many thousands of years old. The dozens of tracks are reassuring. And soon enough hundreds of hand sized offspring will scuttle to the sea in an annual scamble all the more exciting for its status in the food chain as a bloating feast for various birds of prey.

To the same beach at midnight, later in the week. On the northern horizon a cloudy orange glow spreads like daybreak and a mighty low pitched rumble, felt rather than heard, signals the launch, already twice delayed, of a space shuttle carrying an *x* ray telescope into orbit.

No problems, no dramas. The boosters fall away, the flames and long roaring rumble fade. Millions of dollars, a decade of project work and a crew led by a mum whose kids must be watching somewhere soar flawlessly into space. My son, who knows quite a lot about rockets, takes it all for granted, but might be more interested when the *x* ray astronomy really comes on stream.

When all is dark and quiet again on the beach we walk back the few hundred yards to the house. Tomorrow is another day. Holidays are fun: sun, swimming, fishing, tennis, cycling, and the long anticipated days at Disneyworld are what we came for. But now there is more: things seen by night on the Atlantic shore, incidentals ancient and modern, each on its long marvellous journey—the turtle and the space rocket.

Colin Douglas *doctor and novelist, Edinburgh*