

comment

“Most people know little of social care until they have to use it” **DAVID OLIVER**
“As a good doctor, should I follow the policy or the evidence?” **HELEN SALISBURY**
PLUS The butter or margarine debate and lessons from Bridget Jones' diary

WOUNDED HEALER Clare Gerada

We need a complaints code of conduct

The number of complaints against NHS staff is rising, possibly resulting (rightly) from better systems and general encouragement to complain if patients have concerns about their care. Complaints increased by 5% between 2016 and 2017. I have received my fair share of complaints, and all have affected me personally.

Patients must be able to complain when things have not gone as they should. But a complaint, no matter how trivial, is a powerful trigger for mental illness. A survey of nearly 8000 doctors found that 77% who had received a complaint were more likely to suffer moderate to severe depression and had twice the risk of moderate to severe anxiety compared to those with no history of a complaint.

It can even be a trigger for suicide. We can rarely be sure why someone chose to take their own life, but complaints often feature in the narratives of doctors who have done so.

Complaints change doctors' behaviour. Doctors become more cautious and less confident in their practice. Poorly handled complaints often result in dysfunctional behaviour, such as failure to disclose all events, blaming of self and others, and arguments. This hinders rather than fosters learning after a serious untoward incident or “never event” and can harm future patients, sometimes termed “secondary victims.”

A serious complaint can take years to pass through the regulatory system, leaving the doctor stuck in a confusing matrix of fear, uncertainty, and anxiety. The complainant has a tried and tested framework that everyone involved—managers, clinicians, organisations—must follow. Those complained about have no similar framework.

I am medical director of the NHS Practitioner Health Programme (PHP), a confidential service for doctors and dentists with issues relating to a mental or physical health concern or addiction problem. At PHP we have worked with healthcare workers and patients (lay and medical) to develop a draft best practice code for

handling complaints against doctors. The code aims to minimise the harm caused by an already stressful process and to ensure a timely and fair response for all parties. It also aims to balance the rights of patients with those of doctors. Although our code is aimed at doctors, the NHS as a whole should be adopting such a code, or something similar.

The code suggests some basic rights: that doctors be given enough time for reflection before having to give statements (in our experience, doctors tend to “over-admit” their failings), and that doctors have a safe space, with workplace support, to discuss the events. Patients could also benefit from better complaints handling, as it should mean a safer, faster, and more open process and, in the end, better learning all round.

It is important that patients have the right to complain when things have not gone well but also that doctors are supported during the process and are treated with the same humanity as the patients they treat.

Organisations need to understand the effect of complaints on a doctor's mental health. Doing so might help reduce the number of doctors affected by mental illness and who go on to take their lives. Adopting a complaints code such as the one PHP is trying to create would help.

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Complaints often feature in the narratives of doctors who have taken their own lives



Butter or spread? Challenging the views of food zealots

The heated debate about what we put on our bread needs to cool

More than 100 academics recently signed a letter to the *British Journal of Sports Medicine* and *The BMJ* editors criticising them for their “pro-butter” stance and for publishing a “biased” editorial which claimed that the effect of saturated fats on cardiovascular health was grossly exaggerated. A rebuttal followed. What should have been a sensible scientific debate degenerated into a dispute over bias, integrity, and beliefs.

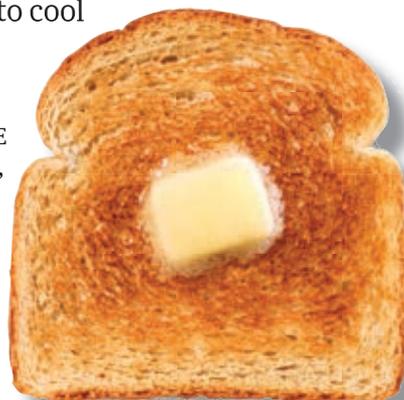
There is a touch of the religious war about these debates, and much of this is because of who controls the sacred nutritional guidelines. The current UK and US guidelines are similar. Both have areas of common consensus that few disagree with—such as eating fewer calories, eating more plants, eating less processed food, and drinking fewer sugary drinks—but when it comes to saturated fat, there is much less consensus.

The fat-diet-heart hypothesis is far from simple. The idea that food cholesterol was to blame for heart disease has been disproven, and replaced by the total fat hypothesis, and then the saturated fat hypothesis. This is based on largely observational (and some genetic) data that low density lipoprotein cholesterol in blood is correlated with heart disease and these levels are slightly increased as dietary saturated fat rises.

Observational studies in poorer countries in different environments (such as the PURE study) have shown the opposite, however, with higher saturated fats (and dairy) associated with lower mortality. No study has successfully shown that a low total or saturated fat diet can reduce heart disease or mortality, and large trials like the PREDIMED study, using high fat nuts and olive oil, have shown the opposite effects, although mainly with total fat.

Food complexity

Another problem is deciding what practical advice to give people, when many foods considered healthy contain some of these fats. The recommendation is that foods containing saturated fats should be replaced with either starchy foods or unsaturated fats. This means, for example, swapping butter for low fat spreads (the rebranded name for margarines). The desperate wish to have a simple message that is applicable to everybody—such as “reduce all saturated fats”—creates the problem. It ignores the complexity and quality of foods, dietary patterns, and individual food choices—and it totally neglects individual variation.



The desperate wish to have a simple message that is applicable to everybody creates the problem

Research thinking is shifting rapidly from food simply being about macronutrients and calories, to consideration of the hundreds of chemicals and metabolites that interact with each other and our bodies and our trillions of gut microbes—which are unique to each of us. Meta-analyses of epidemiological studies show that eating butter containing saturated fat does not, on average, cause harm. There are no long term data on eating modern spreads, although the early trans fat versions we were encouraged to eat were harmful for most of us.

Telling people to eat low saturated fat spreads instead of dairy may force people to consume cheap highly processed items with multiple additives and novel (interesterified) fats that we know little about. Some high quality vegetable based spreads with minimal processing may actually be healthy, but

What can Bridget Jones do for medicine?

Over the holiday season, solving the mystery of an unconscious patient will have been repeated across emergency departments on countless occasions. The holy trinity of legal drug excess, illicit drug use, and organic disease will have been explored through endless scans and blood tests.

When looking after critically ill patients, however, the most effective diagnostic aid is often stolen from right underneath our noses.

The Greeks first encouraged taking a “medical history” in 300 BC and it is surprising how little has changed. Hippocrates’ ancient text would not feel out of place in the paper notes found in my hospital today: “One should pay attention to the first

It would be fantastic to have a contemporaneous record written by the patient who is now unconscious

day the patient felt weak; one should inquire why and when it began. These are the key points to keep in mind. After these questions have been cautiously considered, one should ask the patient how his head feels, or if he has any pain or if he feels heavy.”

What has changed is our knowledge that even a primary source can be mistaken. This is as true when asking patients about their symptom timeline as when asking a witness to describe the perpetrator of a crime.

When the primary source is incapacitated,

we extend our investigation to family and friends who try their best to fill in the gaps. Wouldn’t it be fantastic, however, to have a contemporaneous record of events written by the very patient who is now unconscious?

There are surprising benefits to regular journal keeping, including reduced anxiety and even improved cardiovascular variables. Although the explosion of social media has silenced the paper based Bridget Jones inside us, one in four adults still keep a diary. Reading a patient’s inner thoughts while they have crushing chest pain is unlikely to instil confidence, however, and the personal nature of keeping a journal means it’s unlikely to be acceptable to patients to share their diaries.

people are confused by the messages and ignore these guidelines. Unilever, the market leader, recently sold its spread business, and sales of “natural” butter are increasing at the expense of “artificial” low fat spreads.

Good and bad effects

Two things need to change. First, demonising one major food group or type of fat is a mistake. Foods contain a wide range of saturated, monounsaturated, and polyunsaturated fatty acids in varying proportions, and the different fatty acids never exist in isolation, meaning fats in food can have contrasting good and bad effects on the different functionality of lipoprotein particles. Second, we need to say farewell, once and for all, to the idea of the “standard human.” We are more individual in our food responses than most of us believe. A recent large trial found an equal number of people responded well to a low fat high carb diet as to a low carb high fat diet for weight loss. So one size is highly unlikely to fit all.

It is dangerous to vilify doctors and scientists who criticise guidelines or question population approaches. In the past year we have seen major clinical dogmas—such as aspirin for primary prevention of heart disease or vitamin D supplementation for fracture—debunked by new data. We need critics and debate more than we need outdated inflexible guidelines.

Pass the butter—or the marg.

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Full article with references on bmj.com

But would a palatable alternative be to look at their outpourings across social media? Open access “journals,” including Twitter and Instagram, may allow health professionals to expand their history taking. A colleague recently told me how an unconscious patient’s diagnosis was revealed after a family member showed them the patient’s Twitter timeline. Should we therefore adapt the “social history” section of medical clerking to “social media history”? Would this be acceptable to patients and the profession, and how would it affect the doctor-patient relationship?

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ACUTE PERSPECTIVE David Oliver

Drama of navigating social care

Jimmy McGovern’s recent BBC One drama *Care* was watched by millions and much commented on by the media. The show hit a nerve with viewers and reviewers who’d faced similar issues in their own lives.

Alison Steadman played Mary, a mother disabled by a stroke and vascular dementia. Sheridan Smith played Mary’s daughter Jenny, a woman with work and childcare responsibilities of her own, who was battling to get her mother the care she deserved. In doing so, Jenny faced a disjointed, bureaucratic, short staffed, and sometimes seemingly uncaring system.

The drama had a happy ending of sorts: NHS continuing care was agreed and free to access, and Mary moved to a good care home. The threshold for obtaining continuing care is higher in real life than in the drama, and care home places are increasingly hard to source even when funding has been agreed.

Responses on social media showed that some health and social care staff working with older people were, quite understandably, upset by what they saw as inaccurate representation of their work. They were also upset about being portrayed as uncaring and cold, rather than as victims of an underfunded, understaffed system under pressure. Good people with the right values can find themselves working a system with rules and processes that are anything but person centred and good.

Reactions in mainstream and social media showed that many relatives and unpaid carers for older people identified from their own experience with the story. Previous reports have highlighted similar harrowing experiences for family carers and frail older people in need.

When speaking to audiences of health and care professionals I often ask them to raise their

hands, and keep them raised, if they have been advocating for an older relative and have found it very difficult, despite knowing the system from the inside. They rarely put their hands down.

A recent joint report from the King’s Fund and Health Foundation, based on detailed focus group work with the public, showed general bewilderment at the social care system. Most people have a reasonable working knowledge of the NHS yet know little of social care until they have to use it. They are then surprised to discover that it is means tested, heavily rationed, and based on passing a threshold of need; that part or full payment is often required, and that charges are so high. They don’t understand why some needs come under the label “healthcare” and are free while others, such as dementia, come under “social care.”

At the time of writing, many policy decisions of national importance have been put on the backburner because of continuing Brexit uncertainty. The social care green paper is one casualty of this: originally due last summer, it is yet to be published.

Whatever we decide to do about the funding and delivery of social care, we have a huge job in explaining the social care system to the public and allowing them to prepare for when they may need it.

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A recent focus group report showed general bewilderment at the social care system



When policy doesn't match evidence

GPs, at least the ones I know, are conscientious people who try to keep up to date with developments in medicine and are well aware that much of what they were taught in medical school is no longer true.

We try to keep an eye on research, follow new guidelines, and go on courses that promise to deliver all the latest developments in one convenient—but hard to swallow—CPD day. But what should we do when the headlines and the guidelines conflict?

This year we are being encouraged by NHS England to diagnose pre-diabetes in patients with slightly raised blood sugar and invite them to attend a course to help them make lifestyle changes to prevent or delay the onset of type 2 diabetes. (That word “lifestyle” always makes me think of interior decor and holiday destinations, though I know it means diet and exercise choices in this context.)

There is a cost to the patient in such a diagnosis, in shifting their image of themselves as someone in good health, though possibly a bit overweight, to someone at risk of a serious illness. This may well be a price worth paying if that label is accurate and there is something we can do to help.

Sadly, a systematic review of the evidence shows that we don't have a good way of identifying the people at risk of diabetes,

as the three standard measures—HbA_{1c}, fasting glucose, and impaired glucose tolerance—pick up different groups. Furthermore, although people who complete intensive programmes lasting three to six years do reduce their risk, in studies only 27% of the identified population engaged with an intervention, and the diabetes prevention programme we can refer to lasts only 10 months.

I am very pleased that my patients can access weight loss and exercise groups without charge, and, although I shudder at the thought of joining one personally, I know they work to improve health. However, this approach to preventing the diabetes epidemic, predicted to affect one in 10 of the population by 2034, seems a narrow and feeble response to a major threat. Learning lessons from the success of the smoking ban, we should stop focusing purely on personal choice and individual responsibility and look to transport policy, tax, and food regulation.

Meanwhile, back in the surgery, I need to balance my own doubts about the whole programme against the chance that it may help the patient in front of me. As a good doctor, should I follow the policy or the evidence? And how much of my scepticism should I pass on to my trainees, who have a whole future of navigating these conflicts ahead of them but, in the short term, have exams to pass?

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We should stop focusing purely on personal choice and individual responsibility and look to transport policy, tax, and food regulation

NEW BMJ PODCASTS

Women in medicine

Last month *The BMJ* published a study that looked at physician mothers' experiences of discrimination. The authors, Esther Choo (below) and Eleni Lenos, joined us for a podcast to discuss the results. One of the findings that stood out for them was how “patient lives are put at risk because of disrespect.”

As Choo says: “When women talk about inequity, often people will try to put it back on us—‘have a better attitude,’ or ‘keep going,’



or ‘tough it out’—as if it is just a minor wellness issue. But what we found in our study was consistent with our personal experiences—these examples of discrimination have a major effect on our careers, and because

we are healthcare providers, they have major effects on our patients and healthcare systems. The entire system really suffers when there's not an equitable, safe, and respectful work environment.”

Food and (over)eating out

For many, January brings with it a renewed preoccupation with what we're eating after the indulgences of Christmas. In this podcast we hear from Eric Robinson, author of a recent study in *The BMJ* that looked at the energy content of meals served in UK restaurants. He explains how, since “we're eating out more often than we ever have before, an awful lot of the calories that we're consuming on a daily



basis are coming from outside the home.”

While “there's been a lot of research and discussion about the ills of fast food,” he notes that, before his team's study, “there'd been very little research examining the calorie content of food served in more traditional sit down restaurants.” One of the striking findings of their study was “the sheer number of calories in lots of these dishes”—which Robinson thought consumers would be unlikely to accurately estimate.

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bmj.com highlights is curated by Kelly Brendel, assistant web editor, *The BMJ*





BMJ CHARITY APPEAL

Safe surgeries: helping migrants access healthcare

“No,” the GP receptionist told us. It was “not possible” for the woman and her baby to be registered. She had just gained asylum, and was unable to produce any documents that they would accept as proof of address. Could this be right?

It turns out that I was not alone in my lack of understanding of NHS policy on access to primary care. In 2017, the Doctors of the World clinic saw 1717 patients who were excluded from healthcare. Around 20% of attempts to register the attendees with an NHS GP had ended in refusal. Lack of proof of address, identity, and immigration status were the most common reasons. In fact, NHS England takes an enlightened approach. Its guidance says immigration status is irrelevant to GP registration and that lack of proof of identity or address “would not be considered reasonable grounds to refuse to register a patient.”

Shortly after this, I began working at Cape Hill Medical Centre, a practice

with a strong history of working with marginalised communities. Our patients arrive from more than 50 countries. I have access to (clinical commissioning group funded) telephone translation at the reception desk. We ask for, but never demand, proof of address or identity. We work with patients to accept what proof they can provide. Crucially, we recognise that some, often with good reason, are afraid to share their details.

Fortunately, at practice level, there are several legitimate mechanisms to resist this intrusion into doctor-patient confidentiality. All this good practice is encompassed in the Safe Surgeries Toolkit developed by Doctors of the World. Signing up to this initiative has reinforced Cape Hill’s existing policies and, in joining the Safe Surgeries network, we are marking our commitment to good healthcare for all.

Elizabeth Bates is Doctors of the World GP champion and a GP at Cape Hill Medical Centre, Smethwick

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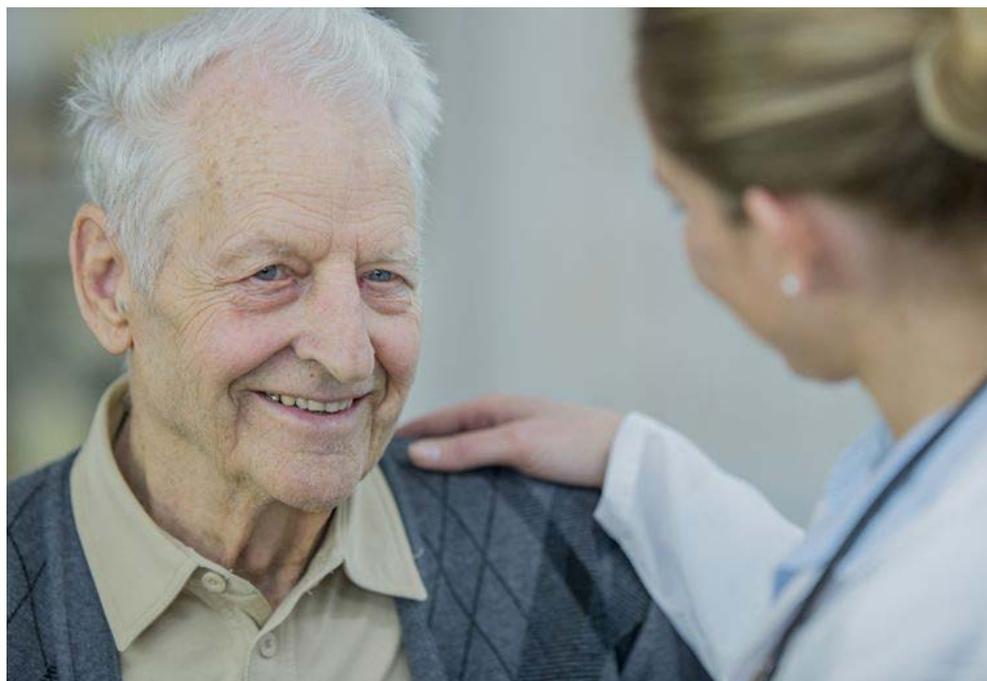
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KEY MESSAGES

- Lack of consensus about what best supportive care is leads to unwarranted variation in the quality and reliability of palliative care that people receive
- A high integrity health system approach should reduce unwarranted variation in practice and be designed around its population's need for proactive, responsive, and person centred care
- Our use of this approach in advanced lung cancer improved the access to and quality of best supportive care
- The model should be transferrable to other patients with other conditions but requires shared accountability across the wider health system



“Best supportive care” in advanced lung cancer—more than a label?

Cancer multidisciplinary team meetings are standard clinical practice in the UK and seek to confirm diagnoses and propose appropriate treatment plans through expert consensus. Patients who are too frail for treatment or who choose not to have it are recorded as being “for best supportive care.”

In reality though, this plan often serves only as a label and fails to translate into anything meaningful for the patient. The team may agree on who should receive best supportive care but there is little consensus about what it constitutes in practice¹ and who should be accountable for its delivery.

The terms best supportive care and palliative care are often used interchangeably but are synonymous only in certain clinical contexts. Palliative care is defined as an approach that improves the quality of life for people, and their families, facing the problems associated with life threatening

Healthcare teams should be accountable for delivering the right care in the right place for people nearing the end of life, say

Jo Bowden and colleagues

illness.² It may be integrated alongside disease modifying treatments or be a plan of care in its own right when such treatment is not possible, so called best supportive care.

A key tenet of quality improvement thinking is that “every system is perfectly designed to get the results it gets.”³ In the context of best supportive care, the absence of a defined standard leads to unwarranted variation in the quality of care that patients receive. Individuals may miss out on the benefits of this care or receive care that is inappropriately medicalised in their last weeks of life. At a system level, this generates inefficiency and, at times, redundancy in the use of healthcare resources.

Mulley and colleagues proposed the concept of high integrity health systems as a sustainable way of overcoming such problems. The emphasis of this approach is on delivering “the right care at the right time in the right place.”⁴ It seeks to deliver effective clinical care within

the limits of what is realistically achievable, without overuse of high cost resources, while prioritising and measuring outcomes that matter to the people they serve.

We discuss how we developed an innovative model of best supportive care to ensure that all people with advanced lung cancer in Fife, Scotland, were offered a minimum standard of care.

Understanding what matters

The catalyst for change in Fife was the recognition that many people with advanced lung cancer were in their last weeks of life at diagnosis, with only a small window to benefit from best supportive care.

One third of patients with a new diagnosis of lung cancer in Fife in 2012 (103/312) were too frail for treatment and therefore needed best supportive care. Median survival was 73 days from diagnosis (interquartile range 31-173). Fifty two patients were supported by specialist palliative care, often in response to a crisis or when close to death.

PRINCIPLES UNDERPINNING IMPROVED PATIENT CARE

Equitable access: Care that is available to all with lung cancer who are for best supportive care
Timely care: Care that is both proactive and prompt
Individualised care: Tailored to needs and preferences of patients, families, and carers
Partnership working and co-production with service users and professionals
Efficient care "no more, no less": Minimises waste of resources

SERVICE COMPONENTS

Identification Specialist palliative care clinician attends weekly lung cancer multidisciplinary team meeting. Other patients from oncology, respiratory, and general practice
Referral to specialist palliative care Within 24 hours of multidisciplinary team meeting
Comprehensive palliative care assessment Home, hospital, or clinic depending on patient frailty and choice
Personalised care planning Immediate action plan agreed with patient, anticipatory care planning started, including do not attempt cardiopulmonary resuscitation (DNACPR), where appropriate
Care coordination Information sharing, referral to other health, social, and third sector services, e-alert, electronic primary care summary, and DNACPR
Follow-up Information sharing, referral to health, social, and third sector services, acute hospital e-alert registered, electronic primary care summary completed

Principles and service components of the new model of best supportive care

Patients, families, and carers described uncertainty about who was overseeing their care and what support they could expect. Some patients received high quality care delivered by a range of professionals, often in primary care, but others received little or no support. This variation in experience was not accounted for by difference in need. Instead, it reflected variation in the system, with professionals describing ad hoc referral routes, lack of clarity around roles, inconsistent follow-up, and suboptimal communication.

Principle driven model of care

The rationale for the development of a new model of best supportive care was informed by baseline evaluation findings, national strategy and guidance,¹⁰⁻¹³ and research evidence of the multidimensional needs of people with lung cancer.^{14 15} Our vision was that the new model would reliably deliver care that was proactive, equitable to access, responsive in times of crisis, and efficient.

Macmillan Cancer Support awarded around £320 000 over two years to support a pilot. We used most of this to fund additional clinical hours (part-time specialty doctor, nurse, occupational therapist, and dietitian).

The absence of a defined standard leads to unwarranted variation in the quality of care that patients receive

The service development was overseen by a multiagency steering group comprising professional stakeholders from health and social care as well as someone who had cared for a close relative with lung cancer, representing the voice of this frail patient group.

Delivering and measuring what matters

The new model of care, summarised in the figure (above), was launched in January 2015. Activity and outcome measures map directly to the principles that underpin the working model.

Robust and proactive identification of patients

The new model of care ensures that patients requiring best supportive care are consistently identified and offered prompt assessment, support, and follow-up. Almost all are identified at the weekly lung cancer multidisciplinary meeting, facilitated by a palliative care doctor.

Following identification, patients are contacted by a specialist palliative care clinician within 24 hours and offered a comprehensive palliative care assessment. Pre-emptive specialist input is offered to everyone, even if they have no overt palliative care needs.

Comprehensive palliative care assessment and care planning

The comprehensive palliative care assessment replaces the need for these patients to attend oncology clinics. It is led by a senior palliative medicine doctor or a specialist nurse, in conjunction with allied health professionals, and takes place in a location that suits the person's needs and preferences. This flexibility provides equitable access to care and addresses the problem that patients who need support the most (the frailest or those with most severe symptoms) are least able to attend clinic.

The assessment is structured but person centred: consultations open with an exploration of patient and family understanding of the diagnosis and an opportunity for discussion about its implications. The consultation evolves into an assessment of symptoms and wider needs, anticipatory care planning, and signposting to other sources of support.

Care coordination and follow-up

Within two days of comprehensive assessment, detailed letters are available electronically to other health professionals in primary and secondary care. Letters contain a summary of patient and family understanding; details of current symptoms and plans for their management; details of discussions about future care, including, where relevant, resuscitation; and a prompt for the GP to update the patient's care summary—an electronic record held in primary care but accessible to most healthcare professionals, including those working out of hours.

Reliable electronically available communication between health services enables the wider system to deliver coordinated and cohesive care. Improved information sharing between allied health professionals working in health and social care has reduced the need for duplication of assessment, enabling social care workers to prioritise those patients and families with the most urgent care needs.

Through shared decision making, we support patients and families

to pursue only the follow-up that is likely to be of benefit. During the first 12 months of the new model of care, 67 hospital appointments, mostly relating to other long term conditions, were deemed no longer necessary and cancelled.

We involve dietetic colleagues to deal with emotive issues around weight loss and eating in advanced cancer. By explaining that weight loss is a normal feature of advancing disease and by sharing strategies to improve the enjoyment of eating, dietitians ensure that patients and families maintain a realistic focus on quality of life rather than weight gain.

When patients are admitted to the acute hospital, we receive an email alert (e-alert) and assess promptly. This enables discussions with acute hospital teams around realistic goals of care and, in turn, earlier discharge planning and shorter inpatient stays. The mean duration of hospital admission was reduced from 9.9 days in 2012 to 6.7 days with an associated reduction in total bed days from 1079 to 624 over the first 12 months of the

High quality care does not need to be synonymous with more expensive care

new model. Fewer patients also died in hospital—41% (42/103) in 2012 versus 32% (32/99). To achieve this, we rely on close working between all members of the multidisciplinary team and, crucially, occupational therapy to facilitate early supported discharge.

This realistic approach to healthcare at the end of life has twin value: the delivery of care directed towards the priorities and preferences of the patient (harm reduction) and enabling more targeted use of the system's limited resources (waste reduction).

Reflections on implementation

Service development at this system level has required intensive and integrated working. Although we have been able to overcome most barriers as a single committed specialist team, it remains difficult to sustain the model of care without additional resource. Furthermore, although we believe that our model is transferable beyond lung cancer, this is likely to require the wider health service to share accountability and resource for delivering best supportive care. The box lists some obstacles and enablers.

Proactive, reliable, and valued care

People with advanced lung cancer in Fife who did not receive cancer treatment are now reliably accessing care that is configured around their needs and preferences. Between January 2015 and June 2018, more than 350 patients have been supported by the new model of care.

The benefits of early palliative care, integrated with disease modifying treatment in cancer and non-cancer illnesses, is well recognised.⁹⁻¹⁷ Although best supportive care is aimed at people who do not receive cancer treatment, this does not replace the need for integrated palliative care. We have now extended our approach to include people who have had some cancer treatment but for whom no further treatment is planned. We continue to support people receiving cancer treatment who have palliative care needs.

At a system level, this project has led to several wider changes in palliative care practice in Fife. In the acute hospital, closer working between health and social care led by

occupational therapy has facilitated a “rapid discharge home” pathway for people in their last days of life, irrespective of diagnosis. Dietetic education around realistic goal setting has been extended to clinicians caring for people with other advanced conditions. Detailed letters are now available to primary and secondary care professionals for all patients who have been assessed by community palliative care (around 1000 patients a year), and the palliative care team receives an e-alert for all patients identified for best supportive care. With extra funding from Macmillan Cancer Support, we are exploring how to adapt and extend the model to patients with other conditions.

National standards of care, known in Scotland as quality performance indicators, are well established in cancer care.¹⁸ However, none relates to palliative care. We believe that healthcare teams should be accountable for ensuring that best supportive care is more than a label, and we are campaigning for a new national standard.

The delivery of high quality palliative and end-of-life care to all who need it is a national priority.¹⁰⁻¹⁹ There is growing interest in the health economics of palliative care interventions and an appreciation that high quality care does not need to be synonymous with more expensive care.²⁰ Our work shows that delivering and measuring what really matters to people enables effective clinical care to be provided without overuse of resources, which are often high in cost but low in value.

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Lucy Johnston, senior research fellow, Edinburgh Napier University

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Enablers and obstacles to the development, delivery, and sustainability of the new model of best supportive care

Enablers

- Published literature showing the supportive and palliative care needs of people with lung cancer and the benefits of early palliative care⁶⁻¹⁴
- Local data showing unwarranted variation in practice and unmet needs
- Recognition by professional stakeholders of the need for clear clinical pathways and improved interprofessional communication
- Recent integration of health and social care in Fife
- Commitment by professionals to systemic change
- Alignment with key strategic policy drivers³⁻¹⁷
- Funding opportunity from Macmillan's Transforming Care After Treatment programme⁵

Obstacles

- Historical culture, practice, and resource issues that don't lend themselves to whole system, person centred care
- Varying levels of confidence and competence in health and social care teams to have conversations with patients and those close to them about what matters to them
- Incompatible electronic communication systems between primary and secondary teams and health and social care providers
- Current financial constraints are a barrier to investment in best supportive care despite evidence of improved care and more appropriate resource use

Gerald Malcolm Stern

Neurologist who was a champion for patients with Parkinson's disease

Gerald Malcolm Stern (b 1930; q London Hospital 1954; FRCP Lond, MD Lond), died peacefully after a stroke on 9 September 2018

Neurologist Gerald Stern was a champion for patients with Parkinson's disease, a widely respected teacher, and an influential researcher whose work advanced clinical treatment. He helped to set up both the Parkinson's Disease Society (later Parkinson's UK) in the late 1960s and the influential Parkinson's Disease Research Group of the UK in the 1980s. Stern was among the first people in the UK to publish a controlled trial of levodopa's efficacy following its celebrated emergence in the US.

Neurology professor Andrew Lees is the co-founder of the Parkinson's Disease Research Group and Stern's "academic son." He says that Stern's bringing together of around 100 neurologists and geriatricians to do clinical trials—unpaid and independent of the pharmaceutical industry—was "quite revolutionary" at the time and led to "some very important findings."

Levodopa

Levodopa (l-dopa), a chemical building block that the body converts into dopamine, is still one of the main drugs used to reduce the impediment of Parkinson's disease some 50 years after it was first trialled in the US. Before then, the disease progressed relentlessly and, apart from stereotactic thalamic surgery and anticholinergic drugs, there was little one could do. Despite these treatments, most patients were severely impaired after five years and dead within 10 years of diagnosis.

Lees, who was Stern's junior colleague at University College Hospital, London, says, "L-dopa improved everything—all the symptoms, the trembling, the stiffness, the slowness—by at least 50% in most patients for sustained periods of time. Gerald was among

the first people to test it in the UK in a Medical Research Council trial, in 1968."

Over time it was realised that l-dopa was "no panacea." Many patients with Parkinson's came to develop disabling fluctuations of motor performance, called on-off effects, and dyskinesias, often having responded well to l-dopa for up to a decade.

Stern, who was a consultant neurologist at University College Hospital from 1965 to 1995, would work on a series of clinical and pharmacological studies in Parkinson's disease. His research included analysing ways of dealing with advanced Parkinson's and capricious fluctuations in patients as the effects of l-dopa wore off. With Lees, he was instrumental in introducing apomorphine into routine clinical practice for the management of refractory on-off oscillations.

In the early 1980s, questions were being asked about whether it was better to start patients with Parkinson's on a dopamine agonist, leaving l-dopa until later when disability was far worse. Stern and colleagues showed that there was no advantage in starting treatment with dopamine agonists or a selective monoamine oxidase inhibitor in most patients. This was highly controversial at the time as it challenged the views of many opinion leaders.

Stern worked with consultant chemical pathologist Merton Sandler (read obituary on bmj.com), researching the potential role of deprenyl, a selective inhibitor of monoamine oxidase, in the treatment of Parkinson's. Deprenyl was not legal in Britain so the team dispatched Sandler to Budapest to secure a one-off supply from a researcher and smuggle it back into the country.

Early career

A wartime evacuee as a child, Stern had no formal schooling between the ages of 8 and 12. He was the "only local boy" accepted at Whitechapel's



Stern's career could be described as "East End boy to papal neurologist"

London Hospital and, knowing little science, struggled with the preclinical curriculum.

He joined the National Hospital for Neurology and Neurosurgery in Queen Square in 1958 after two years in the Royal Naval Volunteer Reserve, mostly served at sea, including in the Mediterranean and Suez.

He became a consultant aged 35, acquiring four beds at St Pancras Hospital, a former workhouse attached to University College Hospital, with further sessions at UCH, Middlesex Hospital, and Queen Square. Stern was president of the Association of British Neurologists from 1994 to 1995. Hadi Manji, who also trained with Stern and became a close friend, says, "Gerald's career could be described as 'East End boy to papal neurologist.' This refers to the time he was asked to see Pope John Paul at the Vatican. His most important legacy, however, will be the large numbers of students and neurologists he encouraged, mentored, and entertained over the years."

Stern stopped seeing patients in his mid-70s but remained active in neurological circles, attending hospital rounds and giving lectures into his early 80s. He leaves his wife, Jenny; three children; and six grandchildren.

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EXCISING THE "SURGEON EGO"

A kinder remedy

Myers and colleagues (Analysis, 24 November) argue that damaging arrogance fills surgical departments. As psychiatrists, we should perhaps be cheering an own goal in the derby of the specialties. Yet we are not, because narcissism isn't just a trait but a defence. We lose interest in others' feelings mostly when overwhelmed by our own.

Surgeons have a lot to manage emotionally. We disagree with Myers and colleagues' solution of "grounded interventions and reliable assessment of key outcomes" to "curb ego driven behaviour": an unemotional approach to an emotional problem. Instead, we argue for some kindness. Balint groups or other case discussion groups help doctors make sense of the emotional difficulty in their work. Doctors can reflect on instead of angrily disowning their feelings. Surgical trainees in our area have been among those asking for such groups, already an essential part of psychiatric training.

The answer is milder, kinder treatment rather than a radical excision of the lesion. But we would say that, wouldn't we? We are, after all, your typical soft hearted psychiatrists.

Alasdair Forrest, ST6 in forensic psychiatry and medical psychotherapy; Murray Smith, ST6 in general adult and liaison psychiatry, Aberdeen

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Tragedies leave scars

Myers and colleagues dwell on the tiny percentage of "super ego" driven surgeons. Surgeons can be shy people, often in emotional turmoil after tragedy but adept at concealing it.

Surgeons literally have patients' lives in their hands. This visceral connection to death is less common among physicians and psychiatrists. Doctors are unlikely to have had



OVER-THE-COUNTER LAXATIVES

Restricting availability could harm patients

The government is being encouraged to restrict the availability of over-the-counter laxatives because of the risk of misuse by people with eating disorders. A further suggestion is that packaging should warn that long term use is harmful.

Many patients with the constipation subtype of irritable bowel syndrome know that regular laxative use controls their symptoms. They don't bother their GP, buying their laxatives over the counter because they are cheaper than on prescription. Anyway doctors might be reluctant to prescribe, assuming that the drugs could damage the bowel. But no convincing evidence exists that modern laxatives taken long term at therapeutic doses damage the bowel.

Restricting availability over the counter would increase GPs' caseload. Given the warnings, GPs may be tempted to prescribe more expensive newer drugs or refer the patient to secondary care. Around a third of the roughly 5.2 million UK adults with IBS have the constipation subtype. The costs could be substantial.

This initiative will only drive people with eating disorders who misuse laxatives to procure them from underground sources. Moreover, it could seriously worry patients with IBS that the treatment controlling their symptoms is harming them. Eating disorders can have a potentially fatal outcome, but so can IBS: 38% of patients attending secondary care contemplate suicide.

Peter J Whorwell, professor of medicine and gastroenterology, Manchester

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an experience that can match, for sheer horror, their patient dying on an operating table. Aortic aneurysm surgery is one of the more graphic examples: alive one minute, dead within seconds.

Do surgeons get counselling after, or are they expected to "man up" and send for the next case as though nothing dreadful has happened? Post-traumatic stress disorder is more common in medicine and surgery than we are prepared to admit. These tragic outcomes leave scars. Surgeons are asked to "play God." It is no surprise if they "act like they are God" at times of stress.

Kevin Newman, consultant orthopaedic trauma surgeon (retired), Guildford

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ROBOTS AND SOCIAL CARE

Lead us not astray

David Oliver is concerned by Ara Darzi's call for full automation of repetitive tasks in health and care (Acute Perspective, 24 November). Robotics may be a useful avenue, but to present care as repetitive tasks ripe for automation is problematic.

Our team's research involves detailed observations of ward staff's bedside care to people with dementia. This care is highly skilled, and routine everyday interactions (including personal care, medication and observation, and meal times) are varied, nuanced, and finely negotiated between staff and patients. It is unclear how

such care could be taken over by automation.

Our research found that emphasising efficiency can be counterproductive, often producing anxiety and confusion in patients and stress and burnout in staff. A focus on numbers may lead us to neglect the systemic reasons behind the mismatch between carers and needs. Attention to what is happening in the highly complex interactions between staff and patient is a key to understanding whether robotics might help.

Focusing on the concept of automating care may, if we are not careful, lead us astray.

Katie Featherstone, reader in sociology and medicine; Paula Boddington, senior research fellow, Cardiff

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Focus on improving lives

Robotics won't solve the social care crisis but could improve the lives of people with care needs.

Oliver notes the high levels of social isolation among older adults. Loneliness among people with care needs is clearly not due to robots but to societal issues affecting how needs are valued. There is little evidence that robots in care increase social isolation. Loneliness is complex, and the presence of other people is not a guaranteed solution.

Social robots could play a part, such as by providing a social bridge to friends and relatives.

In contrast to the billions spent on medical research, the UK has invested, at most, some tens of millions in exploring the potential of assistive robotics for social care, when around 1.2 older million people are estimated to have an unmet care need. The responsible approach is to explore all courses of action to achieve the highest standards of evidence based care.

Tony Prescott, professor of cognitive robotics, Sheffield; Julie Robillard, assistant professor of neurology, Vancouver

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