A PATIENT'S JOURNEY

Mesothelioma

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ABSTRACT
Professor Kieran Sweeney was diagnosed with malignant mesothelioma at age 57. He describes here his thoughts on his interactions with the health professionals who care for him.

I was nearly fifty seven and a half when I left the kingdom of the well. In a final flurry of Cartesian dualism, of course, my mind didn't listen to my body, ignoring geriatric jogging times, inexpressible fatigue, and increasing dyspnoea. A patient of mine with similar symptoms (who had an innocent viral infection) prompted me to seek advice from my general practitioner. Thus it was that on a still, sun silked autumn afternoon, I was infused with the recklessly fearful knowing from my chest radiograph that I had a pleural effusion on my right lung. Probably infectious, said my general practitioner, though I could sense his unarticulated concern. There are many causes, said the earnest respiratory consultant, whom I saw the next day, referring to some "rare aetiologies." It really was only those rare causes that interested me: can we please exclude them, and then I can get back to normal? The pleural tap showed nothing (good), and a pleural biopsy was planned for the next week.

The biopsy was carried out competently by a surgical team who all looked disturbingly downcast after the procedure. None could address my increasing anxiety, except perhaps the most junior member of the team, who, I sense in retrospect, did not feel he had either the authority or life experience to discuss the diagnosis. I was told that while chronic infection could not be excluded entirely, tuberculosis was extremely unlikely, and, yes, mesothelioma could not be excluded. Prepare myself for the possibility of something serious, I was advised.

The specialist nurse came to show my wife and me how to drain the pleural catheter, which was left in to promote a pleurodesis. If there was anything I wanted to know about mesothelioma, he said, with the best of intentions, he had lots of information available. The physical shock of his throwaway remark fractionally preceded its violent emotional impact, but smiling blandly, I went down for a check radiograph, having been invited to do so by the nurse on duty thus: "Could you get this young man to go down for a chest film when you're finished?" My guess is that the nurse was about 22 years old. While I was having the check film, my wife asked the specialist (cancer) nurse why everyone was so downcast. At that point, everyone around knew I had a mesothelioma, except me. I learnt about it by reading the discharge summary over a glass of sauvignon blanc with lunch at home: malignant mesothelioma. "Patient is aware of the diagnosis," said the discharge summary.

The next 48 hours are spent talking to our four beautiful kids, aged mid-teens to early 20s, whose joyous careers are currently sprinkled through school, part time jobs, and university. I can't really convey in words the catastrophic hurt my news has inflicted on them, and it is an insult, which at their age they should never have to endure. I will die of this tumour, I say, and we must address that, neither accepting nor comprehending it. This tumour will kill my body, I say, but I will yield my spirit and personhood reluctantly. We embrace. They weep. I weep for them, for fear for myself, and for the unthinkable horror that they will continue to inhabit the world in which I will play no part. Like my wife, they

A CLINICIAN'S PERSPECTIVE

Mesothelioma is a cancer of mesothelial cells that affects the pleura, peritoneum, pericardium, and tunica vaginalis. Pleural mesothelioma has been recognised as an industrial disease since 1960, when the strong causative association with asbestos fibres was confirmed. Because of the lag time between exposure and onset of symptoms (often about 40 years) incidence in the UK is predicted to peak between 2015 and 2018, although in other parts of Europe that date may be more distant. Mesothelioma was typically thought to be a disease of dockyard workers and engineers, but in a growing number of patients a definite first hand exposure is difficult to define, although they may have been exposed in childhood or have come into contact with fibres through clothing of family members.

Despite the availability of several treatment options randomised trials show little evidence of survival or quality of life benefits. Several trials are ongoing, ranging from the MARS study examining radical trimodality treatment (induction chemotherapy, extrapleural pneumonectomy, and adjuvant hemithoracic radiotherapy) to the use of new targeted agents and viral vectors.

The requirement for an integrated multiprofessional approach to management cannot be overstated. As active treatment options are limited in both choice and efficacy and are associated with considerable morbidity, the role of active supportive care is paramount. Such care may include interventions to manage pain and dyspnoea and to address psychosocial problems. Pain control with conventional agents is adequate for most patients, although some may benefit from cordotomy for intractable pain. Most patients will die within a year of diagnosis.

Treating a colleague can be particularly challenging for several reasons. Often, as in this case, they will have researched their condition thoroughly and may have more theoretical knowledge about it than the clinician they are consulting. Subconsciously this may take us back to a viva situation when our natural response is defensive—we don't want to say the wrong thing for fear of making a mistake, and hence say little.

It is not, however, simply knowledge that we are being asked to bring to the consultation but our experience and humanity. For patients, the realisation of their diagnosis and imminent mortality may undermine their dignity and leave them feeling vulnerable. As healthcare professionals we must shore up their dignity and bolster their self confidence. Thus we might facilitate acceptance of their illness and accompany them on their uncertain journey.

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Seeing the person in the patient

Patients' stories are typically rich in detail, complex, and open to multiple interpretations. They are crafted for listeners: this one for a medical audience. Every story tells a truth, but not the only truth. The doctors in the surgical team, the specialist nurse, and the radiology attendant would all have their own stories about this particular patient. Stories are rhetorical (told to persuade): what is it that this storyteller wants his listeners to understand?

The central act takes place on the morning of the biopsy, the instruction in management of the pleural catheter, and the radiograph. The story persuades us that the professionals are not able to walk in the patient's shoes, but we do not know if it is because the patient is a doctor. Dr Toy says caring for a renowned colleague is a particular challenge, provoking a natural defensiveness and fear of mistakes that make colleagues reticent. The patient himself believes that treating a fellow doctor puts his colleagues in touch with their own vulnerability. The difficulty is that he is "too much like them"; "the horror of what lies before [him] deflects clinical carers from straying on to that territory."

My hunch is that it is more difficult because some people in the room know him personally and because he is a doctor. But my expectation is that other patients would have broadly similar experiences because everyone dealing with them has been left to invent for themselves how to talk and how to behave towards patients and relatives.

Cumulatively, subtly, the unexamined routines and ordinary behaviours inflict grievous emotional harm. Casually but firmly the patient learns that he is completely alone. The professionals can apply their knowledge and expertise; they are efficient and technically competent. But if they ever learnt that, "The treatment of a disease may be entirely impersonal, [while] the care of a patient must be completely personal," they seem to have forgotten. They are unable to make eye contact and they turn a blind eye to patients being stripped of their own clothes, embarrassingly gowned, addressed in derogatory terms, and ordered around.

All of which leads me to question the nature of the multidisciplinary team caring for the patient. What is it? Who does, and does not, belong to it? What do the team members think and talk about together? Do they share the same values? Do they have a common perspective? Have they articulated what they want to achieve for their patients? If their intention is to provide completely personal care, have they worked out the arrangements and processes that could make it a reality? And who is in charge of making it happen?

Providing personal care for patients is phenomenally hard work for individuals and teams. Professor Sweeney's ground rules will improve interactions with patients, but they do not go far enough. The intention to deliver personal care needs to be matched by investment: in practical support for care givers to help them to keep in touch with their own humanity; in training in multidisciplinary team working; and in clinical leadership.

My ground rules to prevent teams from abandoning patients when they most need human warmth and empathy start with:

- Promoting a sense of shared work through a commitment to regular planned communication
- Acknowledging the possibility of miscommunication, investigating how it occurs, and building the processes to prevent it
- Striving to be transparent with one another and allowing members of the team to explore their own questions and vulnerabilities
- Inviting members of the team who know something of the personal life of the patient to share what they know in team meetings
- Reminding team members always to refer to patients by name rather than by diagnosis.

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are brave, selfless, and compassionate.

Thus I am dispatched to the kingdom of the sick permanently and irretrievably. This can never be a pleasant journey, but it can be made at least tolerable, dignified, even. One's guides in this world have a dual role: to read the map and direct you accordingly, but also to be with you on the terrain, a place of great uncertainty. Where one meets the most senior clinical staff, one is left with a sense of technical competence, undermined, with some notable exceptions, by a hesitation to be brave. Eye contact is avoided when one strays off the clinical map on to the metaphysical territory—I am a man devoid of hope—and circumlocution displaces a compassionate exploration of my worst fears. Perhaps, as a doctor, I present an unusually severe challenge to fellow clinicians—I am too much like them—and the horror of what lies before me deflects clinical carers from straying on to that territory. No one can imagine the unimaginable except those, like me, who are experiencing it.

But one's journey to this bleak place can be rendered more bearable if everyone who shares a professional role at the various staging posts bears the bleakness of the terminus in mind. Some simple ground rules could improve the nature of the professional patient interaction, if not actually displace its underlying, transactional mindset.

Please can all healthcare professionals stop asking patients to "Do this for me?" I'm not doing it for them, I'm doing it for me. The key point here is about locus of control. If I am asked, or more often instructed, to do something "for me"—meaning the health professional—then the locus of control for the transaction lies with that person. But the focus of the transaction should be me, the patient. Structured in that way, the "for me" defines the interaction as transactional—I am cared for—but not relational: one is left with the feeling that the professional does not care about me but does something to me.

Please can we avoid crass attempts at humour? There is nothing funny about clutching a plastic bag with all your clothes in, except your pants, socks, and shoes—just stop and think what that must be like—while trying to secure a hospital gown around you, and following, like some faithful gun dog, a radiology attendant who without introduction commands you, with a broad grin to acknowledge his witty lack of grammar, to "follow I!"

The most insensitive observation I am compelled to make is that the more junior ranks of ancillary health professionals are simply unable to conceal the pleasure of the deployment of their authority.

Among clinicians, what individuals and teams think is being conveyed to their patient can be quite different from what is being received, in hints, intonations, phrases, and speculations. The larger the clinical team, the greater the possibility that clinical messages may not be conveyed consistently and uniformly.

In the care I have received, the transactions have been timely and technically impeccable. But the relational aspects of care lacked strong leadership and at key moments were characterised by a hesitation to be brave. What I have always feared in illness was anonymity, being packaged, losing control, not being able to say "this is who I am." In the end, one is left alone, here, in the kingdom of the sick.

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10-MINUTE CONSULTATION

Non-alcoholic fatty liver disease

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This is part of a series of occasional articles on common problems in primary care. The *BMJ* welcomes contributions from GPs

A 45 year old man with known hypertension, type 2 diabetes mellitus, and central obesity presents with fatigue and mild discomfort in the abdominal right upper quadrant. Repeated blood tests show a persistent alanine aminotransferase concentration of 100 IU/l (reference range 10-50) and a γ glutamyl transferase concentration of 80 IU/l (range 10-50) with serum bilirubin and other liver test results in the normal range. He drinks two glasses of wine a month and denies any history of excessive alcohol consumption. Tests (including negative serology for hepatitis B and C viruses) exclude other causes of liver dysfunction. You explain that he is likely to have non-alcoholic fatty liver disease.

What issues you should cover

Non-alcoholic fatty liver disease, the hepatic manifestation of the metabolic syndrome, occurs predominantly in patients with central obesity, hypertension, abnormal glucose tolerance, and dyslipidaemia. It is now the most common cause of abnormal liver function test results, with a prevalence approaching 30% in unselected patients throughout the world.

Fatigue and abdominal pain are sometimes reported but are uncommon. Most patients are asymptomatic and come to attention only because of incidental findings on liver tests or hepatic ultrasound (which you should ask for if you suspect non-alcoholic fatty liver disease). As well as the metabolic syndrome, other disorders can predispose patients to the disease, such as rapid weight loss, starvation, and some drugs (such as tamoxifen and corticosteroids).

No biochemical threshold has been specified for diagnosis of non-alcoholic fatty liver disease, and reference ranges for liver function tests vary between laboratories and the sexes. Patients with advanced liver disease can have normal liver function blood tests so this cannot exclude the diagnosis. Therefore, always consider blood test findings on a case by case basis and remember that persistent elevation of alanine aminotransferase or γ glutamyl transferase, for example, warrant further assessment.

Non-alcoholic fatty liver disease covers a range of conditions from simple "fatty liver" (steatosis) to non-alcoholic steatohepatitis, which can lead to cirrhosis, liver decompensation, and hepatocellular cancer. Non-alcoholic fatty liver disease is thought to be driven by insulin resistance, predisposing to steatosis and inflammation, and subsequently to scarring (fibrosis).

It occurs in patients who have not consumed excessive quantities of alcohol, but it may coexist with and worsen liver damage from any other cause. Conservative levels of alcohol consumption are used as cut offs for diagnosis: no more than 70 g ethanol per week for women (about one standard drink daily) and 140 g for men (two standard drinks daily).

The prognosis depends on disease stage. Patients with simple steatosis have a relatively benign course, with cirrhosis developing in 1-2% over 15-20 years. However, their central obesity and insulin resistance put them at risk of diabetes mellitus and of cardiovascular and renal disease. Approximately 12% of patients with non-alcoholic steatohepatitis and fibrosis progress to cirrhosis within eight years. Currently

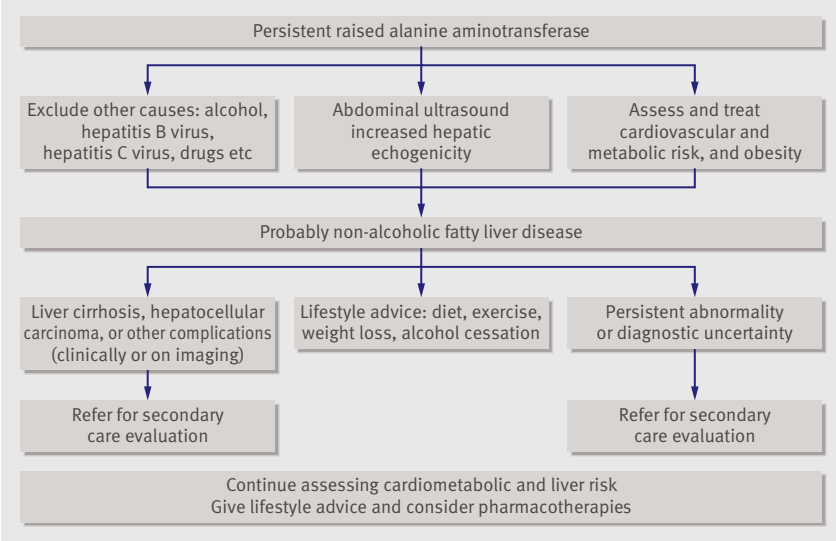
Useful blood tests for the assessment of non-alcoholic fatty liver disease and its complications

Liver biochemistry
- Alanine aminotransferase and γ glutamyl transferase usually raised above reference range
- Alanine aminotransferase usually greater than serum aspartate aminotransferase
- Increased bilirubin and decreased albumin in cirrhosis

Blood count
- Low platelet count in cirrhosis
- Elevated mean cell volume raises possibility of excessive alcohol intake

Coagulation
- Increased prothrombin time in cirrhosis

Metabolic syndrome
- Elevated triglycerides
- Decreased high density lipoprotein cholesterol
- Impaired fasting blood glucose (consider an oral glucose tolerance test)
- Elevated serum uric acid



Suggested diagnostic and referral algorithm for non-alcoholic fatty liver disease

no specific tests can distinguish non-alcoholic steatohepatitis from simple steatosis. However, increasing age, hyperglycaemia, a high body mass index, low platelet count, and low serum albumin are all independent risk factors for advanced liver fibrosis. The gold standard for diagnosis remains liver biopsy, but this investigation is reserved for patients in whom diagnosis is uncertain and to rule out cirrhosis.

Although some evidence suggests that gastric banding surgery, metformin, and most recently glitazones improve liver histology, interpretation is limited by deficiencies in trial design and small cohort sizes. No treatment to date has been shown to alter clinical outcomes, but non-pharmacological measures, such as gradual weight loss and regular exercise, and treatments of the components of the underlying metabolic syndrome remain important. A possible algorithm for the management of non-alcoholic fatty liver disease is shown in the figure.

What you should do

- Diagnose non-alcoholic fatty liver disease with relative confidence if the patient has classical risk factors for the metabolic syndrome, such as a persistent elevated alanine aminotransferase or γ glutamyl transferase, an ultrasound consistent with hepatic steatosis, and if other common or treatable causes of abnormal liver tests have been excluded (such as viral hepatitis, haemochromatosis, Wilson's disease, and alcohol and drug misuse).
- Explain that abnormal liver findings are caused by inflammation that is probably due to excess fat, and that it is most important to treat the metabolic syndrome and its components using non-pharmacological lifestyle measures (such as gradual weight loss, regular exercise, dietary measures, and alcohol cessation) and drug treatments, including hypoglycaemic, antihypertensive, and lipid lowering drugs.
- Assess cardiovascular risk, hepatic complications, and anthropometry (including waist circumference). Ideally any abnormal blood tests should be repeated—ask for a full blood count, liver function tests, serology for hepatitis B and C viruses, autoantibodies (including antinuclear antibodies, antismooth muscle antibodies, and antimitochondrial antibody), iron studies, serum caeruloplasmin, fasting lipids and glucose, and a liver ultrasound.
- Consider specialist referral if you are uncertain about the diagnosis, if the GP or patient are concerned, or if you need advice about pharmacological therapies.

USEFUL READING

For professionals

Angulo P, Hui JM, Marchesini G, Bugianesi E, George J, Farrell GC, et al. The NAFLD fibrosis score: a noninvasive system that identifies liver fibrosis in patients with NAFLD. *Hepatology* 2007;45(4):846-54

Chitturi S, Farrell GC, Hashimoto E, Saibara T, Lau GK, Sollano JD: Asia-Pacific Working Party on NAFLD. Non-alcoholic fatty liver disease in the Asia-Pacific region: definitions and overview of proposed guidelines. *J Gastroenterol Hepatol* 2007;22(6):778-87

Harrison SA, Day CP. Benefits of lifestyle modification in NAFLD. *Gut* 2007;56(12):1760-9

For patients

American Liver Foundation: voluntary non-profit health agency in the USA offering patient information (www.liverfoundation.org/education/info/fattyliver)

British Liver Trust: non-profit medical research charity in the UK offering patient information and support (www.britishlivertrust.org.uk/home/the-liver/liver-diseases/fatty-liver-and-non-alcoholic-steatohepatitis-nash.aspx)

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The best time to go around

As a surgical trainee, I am usually given little choice as to when to carry out a ward round. Yet, I often wonder whether there is an ideal time in the day when the encounter between doctor and inpatient would be most effective.

Recently, after a fairly busy and varied day, I felt the urge to stick around the hospital when only those on call or in shift were around. It was 7 pm, and the sun was starting to set on a warm spring day. The patients had had their evening meals and were waiting for the trays to be cleared. Many had visitors with whom they were chatting; others were looking for some distraction. The atmosphere was less "hustle and bustle" and more "purposeful activity"; the phone rarely rang, as it had incessantly earlier in the day.

This, I found, was the best time in which to get to know patients—to read their notes and discover how they got to where they are now; to find out whether, in the midst of treating their disease, we've been able to alleviate their symptoms; to explain to them test results that had either not been reported to them or simply not explained; and, of course, to share a story or a joke. It's also a good time to ask an unscripted question—to find out what awaits them at home, what they like to read, how their pets must be doing. From that, I could find a role for myself; something I could do to make their stay more bearable and less testing. It could be a matter of prescribing a drug, requesting a test, or setting a plan for the day ahead—but it could also be as simple as pushing forward a jug of water or sporting a reassuring smile. The latter, I found, is rarely ever contraindicated.

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