

Chronic illness: the burden and the dream

"Illness is the night side of life . . . Every one who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick". — Susan Sontag



WERE WE TOO SUCCESSFUL in the 19th and 20th centuries? Public health and medicine vanquished many infections and injury as causes of death and disability in the developed world. But a "burden" of chronic disease now rises to challenge us: chronic disease affects at least one in ten Australians,¹ and cardiovascular disease, chronic obstructive pulmonary disease and depression are endemic.²

It would be heartening to think that a Polypill might be the answer to our (chronic) ills.³ But the problem lies in the fundamental mismatch between 21st century morbidity and 20th century management — and a better match for the former is unlikely to be simple. We're coming to realise, as the World Health Organization has, that "as long as the acute care model dominates health care systems, health care expenditures will continue to escalate, but improvements in populations' health status will not".⁴ Take Zajac's provocative statement on *page 250* of this issue, that "if supermarkets offered the same level of customer service as . . . public hospital(s), they would not survive".⁵ His unique master proposal will turn hospital organisation (and staff leisure activities) on its head. MacDonald (doctor and *BMJ* Assistant Editor, who has scleroderma; *page 267*)⁶ and Fels (ex-chairman of the Australian Competition and Consumer Commission, who cares for a daughter with schizophrenia; *page 268*)⁷ eloquently attest to the deficiencies of our system in this special issue.

How would a revamped healthcare system attuned to chronic illness look? Well, we have a dream. It is that Australia's healthcare system will provide:

- quality Care that is
- Centred on the patient,
- Community-based,
- Coordinated,
- Continuous and
- Cost-effective, and utilises
- Clinical information systems

Can the dream do any better than our current system?

The dream is an evidence-based reality, albeit patchily applied, in several parts of the world. A systematic review of trials testing such chronic care models for people with diabetes showed that these improved health outcomes and lowered healthcare costs or use of health services.⁸ A comparison between Britain's National Health Service and Kaiser Permanente, a Californian non-profit health maintenance organisation (HMO), showed that, although per capita costs were similar, patients in the HMO received more comprehensive and convenient primary care services, faster access to specialist services and inpatient treatment, and used acute hospital services less.⁹ These advantages were attributed to an integrated system (including chronic disease management

programs and partnerships between physicians and administrators) that efficiently managed hospital use, competition and greater investment in information technology.⁹

The chronic care paradigm encompasses preventive and therapeutic care, and both must incorporate risk-factor management. As many of the top risk factors for disease burden (such as smoking and physical inactivity)² involve behavioural change, working in continuous partnership with patients to find common ground is crucial. Such patient-centred care is not a new concept, says Bauman on *page 253*, but is becoming more evidence-based and can increase adherence to management, reduce morbidity and improve quality of life.¹⁰

Evidence is mounting, too, that well-coordinated interdisciplinary teams (intuitively desirable but only recently supported by evidence) can actually benefit people with chronic illness, if team members have the right training, clearly defined roles, and clinical and behavioural skills.¹¹

The evidence that a healthcare system modelled on chronic care benefits its users is compelling.

So what will it take to overhaul the system?

That nothing succeeds like largesse is a belief dispelled by those who argue that it is the *methods* of health financing that must change for appropriate healthcare delivery.^{8,12} Visionary professional and political leaders are vital to the process. For beleaguered healthcare professionals at the frontline, Brooks weighs in with "task substitution" (*page 260*), freeing up some to focus on their particular expertise.¹³ Turf-threatening anathema to some, but perhaps it is more important to ensure that our patients get the best care possible. No one can be all things to all patients with chronic illness.

Nair and Finucane explore the reforms needed for this postmodern approach on *page 257*.¹⁴ The quest requires a shared vision that echoes our dream: to serve society; to foster generalism and decrease fragmentation; to address the changing nature of illness and the changing nature of practice.¹⁵ But, as Nair and Finucane observe, reform will be difficult where health education systems are diffuse, divided and embedded in high-tech, acute or curative medicine, while low-tech chronic and caring medicine is left to drift.¹⁴

The supremacy of curative medicine also spills into our research agenda, where reductionist research currently holds sway. According to Professor A Pettigrew, CEO of the National Health and Medical Research Council (NHMRC) (personal communication), more than 60% of the objectives of current research supported by the NHMRC fall within our National Health Priority Areas (asthma, cancer control, cardiovascular health, diabetes, injury prevention and con-

Care for a man with chronic illness: as it is and as it could be

The reality

Lee, a 44-year-old retrenched bank teller, presents with lethargy and heartburn to his GP, Dr Bilius. The GP orders blood tests (normal, apart from mildly raised serum γ -glutamyl transferase levels) and refers Lee to a gastroenterologist for an endoscopy. This confirms mild reflux oesophagitis. Lee is prescribed proton pump inhibitors, which he ceases as soon as his symptoms resolve.

One night, he presents to hospital with a sore neck after a minor car accident, and tells the medical officer, Dr Stressius, that his perpetual tiredness contributed to the accident. Dr Stressius notes that Lee smells of alcohol, his blood pressure is raised and there is no serious injury. Blood tests (duplicating previous tests) are performed, and Lee is discharged with a letter for Dr Bilius.

Lee loses the letter, but returns to Dr Bilius, who spends 10 minutes chasing the hospital test result by phone. They run out of consultation time, and Lee is advised "not to drink too much". He does not return until injured in a brawl a month later.

The alternative: *We have a dream...*

As Lee presents with a "new" problem, Dr Harmonius takes a full history and examination. A picture emerges of someone with dyspepsia, possible depression, alcohol misuse, high blood pressure, and financial difficulties. Dr Harmonius asks Lee to express his biggest problems ("feeling worthless", "being tired all the time") and goals ("to get a job"), then explains how his problems may be linked; a few of their adverse effects may obstruct his goals. Together, they decide on a management plan to meet his goals: appropriate tests (including a breath test instead of endoscopy,¹⁶ as per Dr Harmonius's ESP — Evidence Support Program), cycling instead of driving, reducing alcohol intake, and possible medication. Lee is happy to return for regular review by Dr Harmonius.

Lee is also referred to a community mental health worker for problem-solving skills and strategies to handle his alcohol problem. He chooses to have his blood pressure monitored by the practice nurse (instead of home telecare¹⁷ or ambulatory monitoring) while he's unemployed. Each time Lee visits Dr Harmonius, the practice nurse initially checks his blood pressure, medications and adherence. Each healthcare professional involved in Lee's care charts findings and interventions in a central electronic database, which they can access with Lee's consent.

At hospital after Lee's car accident, the medical officer, Dr Dextrous, notes from the database that Lee has had the appropriate tests to exclude organic causes of tiredness. Dr Dextrous's own database entry is emailed to Dr Harmonius.



trol, mental health, and arthritis and musculoskeletal conditions). Yet much of the supported research is likely to lead to high-tech curative paths.

Considering its burden, chronic illness must shoulder its own defined and targeted research agenda:

- to identify the factors necessary for successful primary and secondary prevention, then evaluate community-tailored programs arising from these data;
- to explore integrated health delivery systems that embrace our C's for chronic care management;
- to be scientifically rigorous and have meaningful performance indicators, allowing evidence-based decision making.

The Box recounts the experiences of a man with complex chronic problems being let down by the current health system. In stark contrast is his treatment in a dream system evincing the seven C's we espoused above.

Our biggest success with chronic disease will be to live the dream by dragging our healthcare system into the 21st century. After all, "when you cease to dream you cease to live" (Malcolm S Forbes, publishing mogul and founder of Forbes magazine).

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