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VIEWS AND REVIEWS

ACUTE PERSPECTIVE

David Oliver: NHS continuing care is a mess

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Early in my training, English hospitals tended to have a ward or two of patients who were staying indefinitely. Some were on site; some were out of sight in a former Poor Law hospital. Local residents often feared them as places you'd never leave alive. Then came large and rapid reductions in hospital bed capacity, including these wards, even as the population aged and demand rose.[1]

The NHS and Community Care Act 1990 helped accelerate a shift in England towards commissioning more personalised care outside hospital, and it increased means testing for social care in all but the poorest pensioners.[2 3] Years on, the split between needs classified as healthcare (hence free) or social care (means tested) still fragments services and bewilders users.[4 5]

An initially small number of patients with complex, unstable, and terminal conditions remained eligible for entirely NHS funded "continuing healthcare" outside hospital. Access was largely determined by local practitioners' judgment. But, as demand and spending rose, more formal criteria were developed locally, and "light touch" national guidance was issued. Complaints to the ombudsman and landmark legal challenges concerned fairness, and scrutiny snowballed.[6 7]

In 2007 the Department of Health published national eligibility criteria for continuing care.[8] Disputes, delays, and bureaucracy mushroomed as organisations battled to avoid taking on the increased costs. More patients were left waiting in the system, unable to move on.

By 2012 a new national framework standardised screening, decision and support tools, and maximum waiting times, including for "fast track" (end of life) funding and for performance reporting.[9] Still, tens of thousands of bed days are lost each year to people awaiting assessment and funding, through delayed transfers of care.[10]

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If funding for continuing healthcare is refused and social care is required, patients' families may reasonably contest professional assessments and decisions before agreeing to pay substantial costs. Many patients are technically eligible for continuing care but don't currently receive it.[11] Websites and helplines have proliferated to help people appeal.[12 13] Some families appeal even when their loved one blatantly won't meet the criteria—meaning more delay, misery, and frozen acute beds.

Unseemly disputes arise about just how quickly a patient is likely to die and whether it's soon enough to access funding. Huge variation remains in the time taken to make assessments and decisions.[14 15] I've witnessed plenty of gaming and the retreat to organisational interests.

The NHS in England now spends over £2.7bn a year on continuing care,[2] supporting more than 60 000 people.[4] Politicians should simplify the arbitrary rules around funding between health and social care. We've gone from people never leaving hospital to some leaving only if someone can put up bail.

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