

# Patients with advanced co-existing illnesses and their carers face uphill struggle

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Patients in their last year of life with co-existing illnesses struggle to cope with a bewildering array of services and treatments, which are often poorly coordinated and lack any continuity of care, indicates an analysis of patient and carer feedback, published online in *BMJ Supportive & Palliative Care*.

Patients and carers frequently found accessing the support they needed "impersonal" and "challenging," the comments showed.

It's important to get this right, say the researchers, because 'multimorbidity,' in which patients are coping with several illnesses at the same time, is increasingly common in the last year of life, and associated with frequent hospital admissions.

They drew on 87 [semi structured interviews](#) with 37 patients considered to be in the last year of their life from an acute admissions unit in a Scottish regional hospital; a large general practice in England; a respiratory diseases outpatient clinic in London; and 17 [family carers](#).

The interviews took place at 8-12 weekly intervals over a period of five to nine months, in a bid to gauge interviewees' understanding of their various conditions, and their experience of care in different services and environments.

The patients were aged between 55 and 92, and 23 of them were men. They had several illnesses, including: heart, respiratory, liver and kidney

failure; lung cancer; neurological conditions; and mild dementia.

Their feedback reflected an ongoing struggle to cope with several different care systems, services, and staff.

The interviewees described complicated, confusing and, at times, unresponsive services, and the lack of coordination and continuity of care led them to perceive care as inconsistent and impersonal.

No single diagnosis and difficulty explaining their health problems made requesting surgery appointments or GP visits hard, while getting to a clinic was physically demanding for them.

Many of the patients were taking more than 10 different drugs every day, and frequent changes in medication were linked to [hospital admissions](#), making them question the purpose and effectiveness of these changes.

Carers found themselves dealing with increasing physical and emotional demands without any idea of how long they would be required to fulfil this role.

There was little evidence of integrated care planning or any open discussion about the future among patients, family carers, or health professionals.

Patients and carers often coped by focusing on doing the best they could in the here and now, rather than thinking about death. Indeed, most patients put their failing health down to 'getting old,' rather than progressively deteriorating health. Some saw being independent and not having to ask for help or rely on services as important.

"We need a change of culture to encourage proactive care, while at the

same time helping to maintain a sense of identity as a 'normal' old person," write the authors, who advocate a systematic approach to identifying [patients](#) with several advanced illnesses.

This would enable them to live well while planning for the inevitable future deterioration in their health, they suggest.

"More and more of us will face many years of living with multimorbidity: the challenge is to make those years as healthy as possible," they conclude.

**More information:** 'My body's falling apart'. Understanding the experiences of patients with advanced multimorbidity to improve care: serial interviews with patients and carers, rvicees and treatments, which are often poorly coordinated and lack any continuity of care, indicates an analysis of patient and carer feedback, published online in *BMJ Supportive & Palliative Care*, Online First, [DOI: 10.1136/bmjspcare-2013-000639](#)

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