

Patient perspective

Experiencing care of the elderly in the community: a learning curve for carers

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Articles in this journal are concerned with quality and are primarily based on research. In this short article the focus is on the user of the services, the patient and their carer.

In June 2003, a 96-year-old was to be discharged from hospital following a pulmonary embolus and treatment for dehydration. The choices were a nursing home or returning home with a carer. As there was no appropriate nursing home space immediately available and as the family had been told by medical staff that the patient was likely to die ('fade away' was the euphemism used) if sent to a nursing home, the decision was made that the patient should return home with 24-hour care.

Finding a carer

But where to find 24-hour care? A folder containing lists of agencies that provide carers was given to the family who proceeded to contact the agencies. The choice was confusing. Some agencies provide elaborate brochures emphasising the quality of the caring of staff. Some place staff for six weeks, some for much longer. Some state that staff have been given some training, some do not mention training. Some could provide a carer almost immediately, for others it would take some weeks. Some wished to visit the patient and the home prior to placement, some did not. Some were happy for the family to meet the carer, prior to placement, some less enthusiastic. And in the majority of cases it was not clear how the costs that range from £600–£800 per week were calculated, nor did agencies state whether they were registered with a local authority. Such a cost could be paid for out of the patient's own resources, but only for a relatively short period.

Home from hospital

The patient was discharged on a Sunday on continuous oxygen, anticoagulant therapy, steroids and other

medication and with an indwelling catheter. The oxygen had been delivered on the Friday prior to discharge and the system explained to the family who were encouraged by the efficiency of the system so far. A district nurse visited on Monday, clarified that a special mattress and cushion had been ordered, gave instructions about pressure care, contradicted the instructions from hospital about the length of time that the catheter should remain *in situ* and discussed the arrangements for INR (international normalisation ratio) testing. A welcome and reassuring visit for the patient from the GP was paid on the Tuesday. She ensured that prescriptions were up to date and confirmed that advice was available at the end of the phone. On Wednesday there was a visit from a social worker to assess the needs of the patient, a visit that lasted four-and-a-half hours with a reassurance that she would be in touch very soon. The mattress and cushion were due to arrive on Wednesday but came on Saturday, sadly not before the patient had developed a small pressure sore.

Week 2

There were two visits from two different district nurses during the week who gave conflicting information about the care of the pressure sore, one suggesting that the area be covered with a dressing, the other favouring no dressing. Telephone numbers were left to contact when required and a date four weeks ahead made for the next visit. The patient, carer and family began to get into the new routine of everyday living, of encouraging the patient to drink, eat and move and of keeping the patient stimulated.

Week 7

There was a change of carers and a phone call from social services to say that the agency that was being

used was not registered with them. The agency needed to be changed but there was still no information about the financial contribution to care. The carer works six days per week with two hours off each day. The family covers all time off. The district nurse came to check the catheter. The pressure sore was not better and was now causing very considerable discomfort to the patient who complained also that the special cushion was very hard and hurt the back of the thighs. The district nurse had no other suggestions except to walk more. The patient becomes extremely breathless walking. The family ordered a reclining chair, which the patient found very comfortable and which helped to reduce leg oedema. The patient, no longer able to get downstairs, became dispirited.

Week 11

The carer noticed traces of blood in the urine and phoned the general practitioner (GP). A prescription for antibiotic was left for collection.

Week 14

The patient developed chest pain. The GP was informed but declined to visit as chest pain is dealt with in hospital, so ordered an ambulance to take patient to Accident and Emergency. The patient was admitted for two days and discharged with treatment for angina. Squamous cell carcinoma of some skin lesions was also diagnosed.

Week 15

The district nurse visited, diagnosed thrush and instructed the family to buy treatment from a pharmacy, as a prescription will take five days to reach the patient. The cost was £5.49. There was also a four-hour visit from a nurse assessor, accompanied by a representative from social services. The reason for the visit was not explained until the visit, at the end of which the family and carer were told that the needs of the patient were entirely social. They do not satisfy the criteria for a health authority contribution to the care of the patient. The nurse assessor was not prepared to discuss the criteria used. One can only wonder what additional health problems are needed to meet the criteria!

Discussion

The government's strategy for the care of the elderly recommends that where appropriate elderly people should be cared for in their home and following the wishes of the patient; this is precisely what has happened in the case described above.¹ Some readers may wonder where there is a problem. In 15 weeks there has been one visit from a GP, a few visits from the district nurses, one visit and one telephone call from a social worker. However from the patient perspective the success of caring for the frail elderly at home depends on the skill, diligence and quality of those caring for the patient. Just as nurses now carry out some of the tasks that were previously the reserve of doctors, carers now have to be prepared and able to carry out procedures previously done by nurses such as skin care and testing for INR. This is done without regular contact with professionals. In addition the carer must also be alert to situations where something may be going wrong such as early signs of urinary tract infection. But carers do not always know when to ask questions and what to be alert to. Whose responsibility is it to inform carers that antibiotics have an affect on INR results? When prescriptions are left for collection and visits from the GP are minimal, it is easy to see how important information does not get transmitted.

Problems arise when patients no longer have the resources to pay for their care and are made worse by the minimal involvement of social services, a finding supported by Castleton and co-workers.² Cash-strapped social services argue about their contribution. Carers, family and the patient feel degraded when the not inconsiderable health needs of the patient are not considered sufficient to receive a contribution from the health budget. The family find the process exhausting and it is exacerbated by the uncertainty of how future care will be funded. In addition, the time taken by a health professional in a very untransparent assessment based on undisclosed criteria is questionable. Yet the aim of the *National Service Framework for the Elderly* is: 'To ensure that older people are treated as individuals and receive appropriate and timely packages of care which meet their needs as individuals, regardless of health and social services boundaries'.¹

The experience described above is of rather fragmented medical and nursing services and of a service where both GPs and district nurses are over-stretched. This is not the experience of a quality service. The demands that are made on the service are understood but the result for the patient, carer and family is a feeling of isolation. The situation of the frail elderly patient is unlikely to improve, thus demands made on carers and family will increase. In 1999 the Royal

Commission recommended that better services should be offered to those people who currently have a carer.³ When will that happen?

3 Royal Commission on Long Term Care of the Elderly (1999) *With Respect to Old Age: long-term care – rights and responsibilities. Final report.* HMSO: London.

REFERENCES

- 1 Department of Health (2001) *Older People's National Service Framework.* Department of Health: London.
- 2 Castleton B, Dunstan C, Mattocks R and Rowett C (2003) Whole systems approach: from pilot to practice. *Quality in Primary Care* 11: 91–5.

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