Providing support for carers in preventing pressure ulceration

Preventing pressure ulcers is essential for both the patient and the NHS, as failing to do so results in considerable pain and discomfort to the individual, delayed discharge, higher treatment costs and the threat of legal action. In this article, however, I will consider the costs to the family, in particular the carers, and the key role they play in preventing pressure ulcers within the home. To help illustrate these issues, I have focused on the experiences of one family carer and the questions this case raises for community care and carer support.

MY ROLE

I work for a local charity that supports family carers and first visited James and his wife Rachel (names changed) in early 2015. James was referred by his GP practice and had been caring for Rachel since she was diagnosed with multiple sclerosis some 10 years ago.

THE CASE

Rachel spends most of her day in an electric wheelchair and is dependent on others for most of her personal needs. Both she and James are in their early 60s and retired, having sold the family business early to allow James more time to care for Rachel, whose physical problems and lack of mobility mean she is at-risk of developing pressure ulcers.

To manage this risk Rachel is visited by local district nurses who check her skin integrity and pressure risk-level monthly. The local occupational therapy service also provides a stand-aid hoist, a special cushion for her wheelchair and an NHS bed and mattress to help with pressure prevention. An occupational therapist also visits twice-yearly to check the equipment is appropriate for Rachel’s care.

‘Is enough being done to see family members as valued partners in preventing pressure ulcers?’

As Rachel’s primary carer on a daily basis, James is the main barrier to her developing pressure ulcers. He has been provided with information and advice on how to prevent pressure ulcers, and instruction on safe moving and handling, and takes his role in helping to prevent Rachel developing pressure ulcers very seriously. However, this has come at a financial and physical cost — the couple are self-funding and their savings are paying for her personal care needs as well as additional equipment needed to prevent pressure ulcers.

Until January, just one care worker visited four times a day to help Rachel get up in the morning and go to bed at night. Between this, two further visits were needed to help Rachel into bed for two hours in the afternoon, and then up again later. These visits were solely for the purpose of providing pressure relief and preventing the development of any ulcers.

Earlier this year, James had a severe episode of spinal stenosis (narrowing of the spaces in the spine) leaving him unable to help with Rachel’s care. This meant the couple had to increase the number of visits to two care workers four times a day.

James’ back problem was probably aggravated by his years of caring for Rachel, especially when lifting her without the appropriate equipment or knowledge of moving and handling.

Sadly, James is not alone — a 2012 survey of carers showed 36% had sustained injuries resulting in back pain (www.hscic.gov.uk). James is another casualty of the care system and a reminder that sometimes there can be a cost to the carer’s own health.

WHAT DID I LEARN?

Supporting this family brought up some significant challenges:

- Would the outcome have been different for James if he had been identified as a carer sooner and referred to carers’ support services?
- Should there be limits to what a family should be expected to pay in terms of funding for the care needed to prevent pressure ulcers?
- Would Rachel have received any help with pressure ulcer prevention from her local NHS services if she had not been able to pay for this care herself?
- Did James’ journey as a carer present any opportunities for partnership working between the NHS, family carers and the voluntary sector?

During the course of my work I am often left wondering whether enough is being done to help family members become valued partners in preventing pressures ulcers, or even if the cost to carers’ and family members’ health is properly recognised. I hope this small piece goes some way to highlighting the pressure carers are under out there in the community. JCN