People with dementia need care champions

THE COMPLEXITY of residents’ needs in care homes and the importance of a 24-hour registered nurse presence have been highlighted by Hazel Heath (Nursing Older People, 23, 4, 6). I agree that care home nurses should value their work and have confidence in their knowledge, skills and practice. However, to meet the complex needs of people with dementia in such settings is a challenge for anyone.

Care homes, more than hospices, are major providers of end of life care for people with dementia. About one fifth of UK deaths occur in care homes and not all provide excellent palliative and end of life care. Most people say they would like to die in their own home, usual residence or care home yet the figure of 60 per cent of deaths in acute hospitals is set to increase. Residents are often transferred to hospital where they die in unfamiliar surroundings.

While residents die from diseases such as stroke, respiratory illness or Parkinson’s disease, an estimated 75 per cent will have co-morbid dementia. Dementia is a ‘life-limiting’ illness and an independent cause of mortality. Many residents have advanced dementia, which has a median survival of 1.3 years, similar to that of well-recognised terminal diseases such as metastatic breast cancer. Yet people with cancer often receive better palliative and end of life care.

Care homes are major providers of ‘hospice care’ for people with dementia. But surely recognising the complex requirements of this population can only strengthen the call for a 24-hour nursing presence?

I urge RNs in care homes to be champions for people with dementia who have the same right to quality palliative and end of life care as other residents.

Karen Harrison Denig is practice development lead, Admiral Nursing and member of the RCN older people’s forum steering committee.

Taking the stigma out of dementia

THE OPINION article by Gwyn Grout in the October issue of Nursing Older People (23, 8, 9) notes that, as part of the Butterfly Scheme, carers of people with dementia are asked for information about their relatives.

The RN’s dementia project has identified involving carers as a priority, alongside staff education. The Butterfly Scheme’s near-100 per cent opt-in rate gives a clear message about what carers want.

The Butterfly Scheme only uses carer input when the patient cannot reliably provide that input, and even then there is absolutely no bypassing of the patient. This is an important part of the scheme’s teaching which delivers a resoundingly positive response to people with dementia. Butterfly Scheme leads are always delighted by the turnaround in attitude towards dementia care that happens so quickly on implementation of the scheme.

I would be enormously saddened by any suggestion that a mental health condition is irrevocably associated with stigma and disgrace. Clearly, carers feel this is the time for change.

Should we empower patients and carers to request the use of signs to initiate an individualised care response? If the signs are part of a proven, positive, education-based scheme, I think the outcomes of the RCN dementia project give us our answer. If some people prefer not to take up the option, they can simply turn it down and allow those who want it to move towards a positive, destigmatised future for people with dementia.

Barbara Hodkinson, founder and co-ordinator, the Butterfly Scheme

Book reviews

Dignity in Healthcare – a Practical Approach for Nurses and Midwives
Milika Ruth Matiti and Lesley Baillie (Eds)

DIGNITY IS important for all patients of all ages but it can mean something different to each person.

Ethical expectations for dignity in care are examined, as are environments that support dignity. The authors consider staff behaviour and attitudes, patients with mental health issues and older people.

The chapters are well set out, combining evidence-based theory with scenarios for practical application. This book will be a useful resource on wards and will provide a good grounding for pre-registration healthcare students.

Bever Al-Azzawi, practice development nurse, Northampton General Hospital NHS Trust

Long-term Conditions – a Guide for Nurses and Healthcare Professionals
Sue Randall and Helen Ford (Eds)

THE EDITORS highlight the need to become more informed about chronic disease and long-term conditions.

The book’s sections are easy to follow. They cover the basics of nutrition, living with chronic pain, depression, assistive technology, workforce design, education, training and self-management.

This excellent book takes a needs-led approach. I particularly liked the points for reflection that encourage readers to develop their own practice to improve patient experience. There are links to additional reading and online resources.

Mike Jackson, community staff nurse, East Lancashire Hospitals NHS Health Trust