One size fits all: palliative care for people with learning disabilities

The End of Life Care Strategy takes as inclusive an approach as possible, but can it make a difference for people with learning disabilities who are dying? Therefore we must ask ourselves 'Does one size fit all?'

It is estimated by the Department of Health (2001) that approximately 2% of the population have varying degrees of learning disability, with 1.2 million people having a mild to moderate learning disability and an additional 210 000 people having a severe learning disability. Brittle (2004) suggests that all individuals within this client group have special needs when they enter the health-care system. In addition, most have greater health needs than the rest of the population and are more likely to experience mental health problems and chronic illnesses (Barr et al, 1999).

The NHS Plan (Department of Health, 2000) challenged the NHS to change its services and cater for the needs and preferences of individual patients, their families and carers. The following year, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001) highlighted the government's commitment to enabling people with learning disabilities to access health services designed around their individual needs with fast and convenient care delivered to a consistently high standard, and with additional support where necessary. This was the first review of services for people with learning disabilities in 30 years and focused on four key themes to improve the care of people with learning disabilities: rights, choice, independence and inclusion.

Since then, *Valuing People Now: a new three-year strategy for people with learning disabilities* (Department of Health, 2009) has set out the government's strategy for people with learning disabilities for the next 3 years. It also responds, following consultation, to the main recommendations in *Healthcare for All* (Michael, 2008), the independent inquiry into access to health care for people with learning disabilities.

The number of adults with a learning disability is increasing by 1.1% each year and as life expectancy increases age-related diseases such as stroke, heart disease, chronic respiratory disease and cancer are an increasing problem. For example people with Down's syndrome have a higher than average incidence of dementia, diabetes, epilepsy congenital abnormalities and leukaemia, thus the death rate of this client group is higher than the general population at a younger age.

Despite these problems, repeated surveys and studies over more than a decade have found shortfalls in primary care and hospital provision. *Death by Indifference* (Mencap, 2007) highlighted the difficulties faced by people with learning disabilities in gaining access to help, in part because of the inexperience of health-care staff in working with people who have difficulties in communicating. The shortfall in care identified in this report triggered the launch of *Healthcare for All* (Michael, 2008) which highlighted the need to improve access and outcomes in general health-care services for people with learning disabilities.

Providing care for any individual approaching the end of his/her life is a skilled role and without support and information, staff and carers can find the experience overwhelming. However, the individual's ability to cope can be increased by having appropriate information available.

The End of Life Care Programme (Philip and Richards, 2006) was launched with the aim of improving care for people coming to the end of their lives, irrespective of their diagnosis. It seeks to provide greater choice for patients with regard to their place of care and place of death, reduce the number of emergency admissions to acute care for those who have expressed a wish to die at home, and reduce the number of patients transferred from care homes to acute care within their last week of life. This can be especially pertinent for people with learning disabilities who are often left with no or poor choice regarding their place of care.

More recently the national End of Life Care Strategy (Department of Health, 2008) is the first comprehensive framework that aims to provide high quality care for all adults at the end of life. The main focus is to increase public awareness and discussion of death and dying and to ensure that all people are treated with dignity and respect at the end of their lives.

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Mary's story

Mary was a 55-year-old woman, with the dual diagnosis of a moderate learning disability and mental health problems, who lived independently. She had a daughter, Kate, who also had a learning disability and lived with support in a small community home. Deterioration of Mary's mental health resulted in admission to a learning disability inpatient unit for assessment and treatment.

As Mary's discharge approached, she began to have problems with rectal bleeding and constipation and was referred for further investigation. The results were initially reported as normal, but 10 days later Mary presented with distension of her abdomen, extreme sweating and pallor resulting in an emergency admission to the local hospital. A computed tomography scan revealed multiple lesions in her liver and a mass in her caecum. Mary underwent a right hemicolectomy as a palliative intervention.

Although the learning disability nurses supporting Mary had a therapeutic relationship with her, enabling effective communication, it was unclear how much Mary had been told about her cancer diagnosis, so she was referred to the Macmillan nurse for people with learning disabilities, Diane. Diane became pivotal to Mary's care, providing physical and emotional support. She confirmed with the colorectal team that Mary had been given relevant information, including the news that her cancer was not curable thus requiring a palliative approach.

Mary returned to the learning disability unit after her surgery, where she was encouraged to share her recent experiences while in hospital, exploring what she understood about her illness and how she thought it may affect her future life. Mary described some of her physical symptoms and her version of events indicated she was aware her illness was serious, but that she did not know exactly what was wrong with her. This mirrors the theory that people with learning disabilities relate to their illness by describing symptoms rather than understanding the cause (March, 1991).

It was important when talking with Mary to pitch the conversation at a level she could follow and understand, using simple language and basic vocabulary, e.g. Mary often said that 'it would be nice to get better', leading the discussion to how medicine could help her to feel better but it would not remove the cancer.

Mary expressed a greater awareness as her illness progressed, speaking openly about dying without distress, saying: 'I know I am going to die, I just don't know when'. Her main concern was that she would be transferred back to the acute hospital, as she wanted to remain in the unit until she died, with Kate continuing to visit. To formalize Mary's wishes the preferred priorities of care document was completed (Storey, 2003). This allowed everyone who was important to Mary to have their thoughts, preferences and wishes regarding Mary's care and her place of death to be documented. Everyone involved felt Mary gained a sense of relief and peace as well as pride in having a preferred priorities of care document.

As Mary reached the terminal phase, Kate began to demonstrate some difficult behaviour. Kate spoke about her mother's illness and impending death, and became distressed that she would not have another Christmas with her mother. It became apparent that the changes in Kate's behaviours were actually expressions of her grief. This situation was partly resolved by giving Mary and Kate an early Christmas, with traditional decorations in Mary's room.

Mary died peacefully 4 days after her special Christmas day and although Kate was not present at the death she visited the unit afterwards and spent some time with her mother.

Discussion

The Valuing People document (Department of Health, 2001) defines learning disabilities as:

- A significantly reduced ability to understand new or complex information, or to learn new skills – 'impaired intelligence'
- A reduced ability to cope independently, which started before adulthood, with a lasting effect on development – 'impaired social functioning'.

Familiarity and trust

Mary's resettlement reflects policy that states 'people with learning disabilities have the right to live in their local communities' (Royal College of Nursing, 2006).

People with learning disabilities often have difficulty adapting to new situations and hospital or even hospice admissions can be a profound change which causes them distress. Brittle (2004) suggests that strategies should be in place within acute services to minimize the effects of hospitalization on people with learning disabilities. In Mary's case this was not possible as she was admitted as an emergency, preventing any planning for her admission which compromised her ability to cope with treatment and care provided by the acute services.

Resources and support for staff

Jones (2003) suggests that the interventions of a learning disability nurse can minimize the difficulties health services, including palliative care services, have in caring for people with learning disabilities, as these practitioners are able to transfer their skills to support the process of people with learning disabilities receiving appropriate health care.

Reduce the fear factor

The aim of the Macmillan nurse working with the learning disability team was to build up a therapeutic relationship. Caring for someone with cancer was a new experience for most of the staff and they were apprehensive about whether they could meet Mary's needs as her dis-

ease progressed. Mary's case highlights the need to ensure that learning disability staff teams are given support and education to facilitate good supportive or palliative care when nursing individuals with life-limiting or life-threatening disease. It was therefore important to offer support and encouragement to the team, enabling them to fulfill this role. Tuffrey-Wijne (1997) emphasizes that close cooperation between all professionals involved will improve emotional support for both the patient and his/her family.

Effective communication

Many studies such as Jenkins (2005) and Jones (2003) support the concept that people with learning disabilities may not be well cared for in a hospital environment, where negative attitudes and ignorance among healthcare staff still exists. Beange et al (1995) stated that one of the main barriers to medical assessment is communication. In view of these barriers Brittle (2004) suggests that nurses should ask themselves: 'what would I do if I were in a strange place, with strange people, who do not interact with me?' Appropriate communication with patients is an important aspect of the nurse's role and may help patients comply with nursing interventions.

Tuffrey-Wijne (1997) advocates thorough assessment of a person's understanding of his/her illness as this may affect the way he/she copes with it; input into Mary's care clearly focussed on this. Effective communication is an important component in palliative care and nurses are in a privileged position of being able to listen to patients about their hopes and fears (Dean, 2002).

Communication difficulties are prevalent in many people with learning disabilities and can occur in a wide range of conditions. Meaningful communication with these individuals depends on the ability of carers to recognize and translate many different idiosyncratic cues. Regnard et al (2007) concluded that carers appear to be intuitively skilled at identifying distress cues but have little confidence in their observations. Mary's case also illustrates that people with learning difficulties, if allowed time, space and trusted carers, may understand and wish to discuss potentially difficult subjects such as death and dying. A paternalistic attitude that tried to 'protect' from distress, assuming such people cannot 'cope' with it, would not have been helpful for Mary.

Use of pain tools

To help the process of identifying and alleviating distress a number of pain tools have been developed, but the use of such tools is not congruent with the lack of evidence that pain has any specific signs or behaviours.

An observational tool, such as the Disability Distress Assessment Tool (DisDAT) (Regnard et al, 2007), which is used to document content and distressed states, can be very successful in identifying such cues. It can be completed in a number of ways, e.g. proactively and referred to when necessary or at a time of crisis, but always in collaboration with friends and family. Including others in the completion of the tool makes it is less likely for the professionals involved to 'miss' any symptom that relies on verbal reporting and thus appropriate symptom control can be delivered, monitored and evaluated.

Dealing with diagnosis

Mary and Kate avoided focusing directly on Mary's diagnosis and, as highlighted by Flaming (2000), this may have been a coping strategy or may have been a part of Mary and Kate's spiritual dimension. Swinton (2006) offers his insights into spirituality and spiritual care as relevant for all people including those with learning disabilities, indicating that people with learning disabilities have the same spiritual needs as the generic population.

Tuffrey-Wijne (1997) suggests that people with learning disabilities have a profound need for relationships and are gifted at forming satisfying bonds. The need to communicate more strongly when ill was visible in Mary's desire to focus on her contact with Kate, and in her wish to interact with others on the unit. Buckman (2000) advocates that once patients have begun to verbalize their thoughts and feelings it is important to let them explain at a pace that seems comfortable. Reiteration and reflection of patients' statements show they are being listened to. Tuffrey-Wijne (1997) suggests that people with learning disabilities are very perceptive and may realize that they are going to die even if they have not been told. Fallowfield and Jenkins (1999) report that many patients would welcome the opportunity to discuss their fears, and suggest that it is a key skill of the nurse to recognize these moments. People with learning disabilities may require additional support to voice their anxieties.

Shared models of care

Mary's story highlights the need to ensure learning disability staff teams are given appropriate support and education in order that they may facilitate good supportive and palliative care when nursing individuals with life-limiting or life-threatening disease.

For people with learning disabilities, their families and carers an assurance of equitable palliative care services is needed. There needs to be recognition by health and social care providers of the important role that families and carers play in providing valuable background information, as well as training in end-of-life care for people working within learning disabilities services. There also needs to be an increase in practical information for direct care staff and wider use of accessible resources and information around illness and bereavement as highlighted within the End of Life Care Strategy.

Conclusions

To answer the question can the End of Life Care Strategy meet the palliative and end-of-life care needs of people with learning disabilities, does one size fit all, really depends on the interpretation and delivery of the strate-

gy across services. This is a crucial component when planning the future provision of palliative care for people with learning disabilities.

We should anticipate, be proactive rather than reactive, and work with our colleagues from all specialities. We should also challenge practice, attempting to change ways, cultures and assumptions, teaching and informing families, carers and professionals who are involved in the care of the individual. In this way we will begin to advocate and improve care for this vulnerable group of people. After all: 'Nothing would have greater impact than to act on the knowledge we already have' (Stjernsward, 1993). **BJHM**

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KEY POINTS

- The number of people with learning disabilities is increasing by 1.1% each year.
- In general people with learning disabilities have greater health needs than the generic population.
- The need to provide equitable health-care provision for people with learning disabilities is well documented within recent national policy and guidance.
- The role of families and carers in providing care, including end-of-life care, needs to be more widely acknowledged by services.
- Proactive planning of services rather than the provision of reactive care needs to be considered by all agencies, in order that the end-of-life needs of people with learning disabilities are appropriately met.