I’ve been made to feel like a number, not like a person

**THE PATIENT**

Lynn Mitchell has COPD. Here she explains the contrast in her experience of hospice and hospital nursing care.

Since the age of one I’ve been asthmatic. I also have COPD, bronchiectasis and angina, am in a wheelchair and need oxygen. I haven’t been able to access palliative care on the NHS – in fact one consultant told me it’s because it will take me too long to die.

But I’ve had help from my local, charity-funded hospice. They offer respite care so, over the years, I’ve spent anything from a day to a two-week stay there. The one-to-one nursing care is lovely; nothing is too much trouble for the staff. They make sure you keep your dignity and safeguard your privacy. I was worried about being naked in front of them when having a bath so they gave me a small towel to cover myself, to save me feeling embarrassed. Nurses there never talk down to you; they treat you like equals, never rush you and make time to chat with you. And they say it’s OK to cry and to be angry about your condition.

This care is different to some of the other nursing support I’ve had in hospital. There I’ve been made to feel like a number, not like a person. Sometimes nurses have left me in tears – the way they talked to me made me feel like I was a pain and a nuisance.

Once when I was admitted to accident and emergency because my oxygen levels were low, I was placed in a side room that stank of pee and I didn’t even see a nurse. Another time I was in a mixed admissions ward where a man kept exposing himself. I was really embarrassed and wanted the curtains pulled around me but the nurses said they weren’t allowed to do this. In the end I was so distressed I discharged myself from hospital. I couldn’t stand the way I was treated. I would rather die, with my family around me, than go back there.

I don’t blame the nurses in hospital – it’s not that they want to be horrible to patients, it’s that they just don’t have the time to reassure us. It’s the system that stinks. But the nurses at the hospice have the time to listen to patients, to answer our questions and help us when we’re down. They hold our hands and give us hugs.

We need more nurses in acute care who are trained in palliative care. I’d like nurses to treat patients the way they’d like to be treated – that means respecting our dignity and making us feel safe.

**EXPERT COMMENT**

Most nurses enter the profession with feelings of compassion and care. What has happened? The care this patient is experiencing in hospital is appalling and not to be tolerated. Basic dignity, care, understanding, sympathy and a kind word or gesture can go a long way to making patients feel safe, valued and supported.

The COPD disease trajectory is uncertain and many patients experience a slow decline, interspersed with frequent exacerbations requiring emergency admission to hospital, often with non-invasive ventilation. Many adapt and cope but nurses must be able to recognise when patients are struggling physically, psychologically and emotionally. They need to learn how to listen and pick up cues, initiate difficult conversations, prioritise what is really important in the ward, and deliver patient-centered care irrespective of hospital or ward targets.

The end of life care strategy applies to patients with chronic illness, including COPD. One vital principle is that patients are treated as individuals, with dignity and respect. Other key aspects include initiating discussions about preferences for care, agreeing a care plan to reflect those discussions and delivering quality services in all locations. The strategy may be a tall order – particularly in acute care where nurses are trying to meet management needs, reduce A&E waits and improve efficiency – but nurses must learn from hospice care and apply those lessons to patients with advancing COPD.

**Learning points**

- All patients should be given privacy, treated with dignity and respect, and their wishes should be explored.
- Every patient’s needs are different. Take time to talk to patients to understand their fears/anxieties and listen to their concerns. Distressed patients can often work out their own solutions but just need to talk to someone who will listen to them.
- Improve your communication skills. Talk confidently with your patients about difficult subjects. Learn from models of care developed for cancer, and apply them to patients with chronic advancing disease.

ARNS have developed a course for clinicians managing patients with advancing COPD: www.arns.co.uk/Courses

The British Lung Foundation provides an online breath test for people who are worried they might be at risk of COPD. To find out more about lung disease visit www.lunguk.org or call the BLF helpline on 08458 505020

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