



Opening up hospice care

In its 50th anniversary year, Britain's world-leading hospice movement is campaigning to increase access to its round-the-clock care, writes **Judy Hobson**

IT CAN be hard to be a '24/7' carer for your nearest and dearest when they have a terminal illness and you're in your 70s yourself. The charity Hospice UK is aware of this and keen to offer support.

In the 50 years since Dame Cicely Saunders established the first purpose-built hospice in Sydenham, south-east London, to provide palliative care for those with terminal and life-limiting conditions, the hospice movement has grown and become all-embracing.

In addition to being provided in the 220 hospices throughout the UK, hospice care is now also being taken into people's own homes. This means more than 200,000 adults and children are getting physical, emotional and social support thanks to the movement Dame Cicely began. Sadly, though, there remains a huge unmet need for the special kind of

individual compassionate care that hospices offer which also gives comfort to anxiety-ridden partners and parents.

Lord Howard of Lympne, who as Michael Howard was Home Secretary and later leader of the Conservative Party, is chairman of Hospice UK.

He says: "We believe there are another 100,000 people who could benefit from hospice care but are not getting it, so our priority in this, our 50th anniversary year, is to expand our operation so that anyone coming towards the end of their life receives this kind of support. Rather than providing extra beds in hospices it means offering more care at home because most people would prefer to die there.

"We also need to raise awareness so that all those who would benefit from hospice care can get it. Some GPs are very good at referring people but some are not. We're

talking to the Royal College of GPs about improving GPs' knowledge of the services we provide. Too many family members, on hearing about what we do when they have just lost someone, say 'if we had only known about hospice care'. We're also encouraging local hospices to make contact with the GPs in their area."

Research conducted by the charity shows that one in four families in need of hospice care is not receiving it, which is placing a heavy burden on their closest relatives.

It hopes that its campaign Open Up Hospice Care will result in more people being able to end their days with peace and dignity in the familiar surroundings of their own home or in the local hospice they have come to know.

The charity's newly appointed chief clinical officer Carole Walford sees her principal task as improving and widening

hospice care. She says: "Our aim is to reduce the number of people dying in hospital and to give them a choice as to where they die."

Currently around one third of adult hospice care is funded by the NHS.

Lord Howard says: "By doing what we propose, we'll save the NHS money and free up hospital beds. To carry out this

project I estimate we will need an extra £80m a year from the NHS but it will save much more than that."

"But," Carole points out, "a hospice is not simply a place to die. Many people go there for a few

days every now and then to give their carer, frequently a partner, a break.

"Your hospice's clinics and day services will help sort out your problems and enable you to cope with the news of your diagnosis, your pain and emotional stress. We understand and listen, and by intervening we offer family members who are often exhausted from all the caring they've been doing some respite, and this gives them the opportunity to then have good, meaningful conversations with their loved ones."

She urges those with life-limiting illnesses and their families to approach their local hospice at an early stage.

"It is important that people have those vital conversations about how they want to spend their final days early on. Your nearest and dearest need to know whether you want that care to be at home or whether you'd rather be in a hospice.

"Some people don't mind having their bed in the living room, but others don't want to leave their families with that memory and would rather be in a hospice, particularly if they have got to know it well through having respite care there, or by attending its clinics and therapy sessions. Having that conversation when you're still able to is the one chance you have of getting it right."

Helping people cope with the pain and the distress of being told they have a terminal illness are prime goals of the hospice movement. "Just having someone

there at the time to support you and hold your hand can help," Carole says.

"Often this is one of our trained volunteers. They allow the family member to have a break and will be there to support the family from diagnosis, during the illness and after the death."

Being creative can help people to deal with their situation, and some hospices run

"In partnership with the NHS we want to widen access to hospice care so that more people can die in the familiar surroundings of their own home or their local hospice"

**Hospice UK chief clinical officer
Carole Walford**

art groups and creative writing sessions, which allow people to express their feelings through painting and poetry. "What we give is person-centred care. We do this by finding out what is most

important to that individual. We're also keen to keep them as fit as they can so we provide physiotherapy and occupational therapy to help them maintain movement.

"Where pain is concerned, we can always help to relieve it, but first it is important to listen to the patient and understand what might be causing it. Sometimes something as basic as a heat blanket or changing their position can help."

Lord Howard was asked to become chairman of the charity after leaving the

House of Commons in 2010. He says: "I was very happy to get involved because I knew about the splendid work hospices do. If you go into a hospice, you enter a very special place and that's because of the very special people who work there.

"In this, the 50th anniversary year, we should be proud of the fact that this movement, started in the UK, continues to lead the world in the provision of palliative care.

"To continue the work Dame Cicely began and to ensure that everyone in the UK who needs it can benefit from hospice care we need the public's help. When you get to know what they do, you realise how deserving of your support hospices are.

"I believe they have a special place at the heart of the community, and that is why they're one of the best-supported charities in the UK."

Find out more

■ To access hospice care, you or a member of your family can self-refer by ringing your local hospice. Alternatively, your GP can refer you or, if you are an in-patient, your hospital can

■ To find a hospice near you, tel: 020 7520 8200, log on to: (www.hospiceuk.org) or e-mail: (info@hospice.uk.org).

