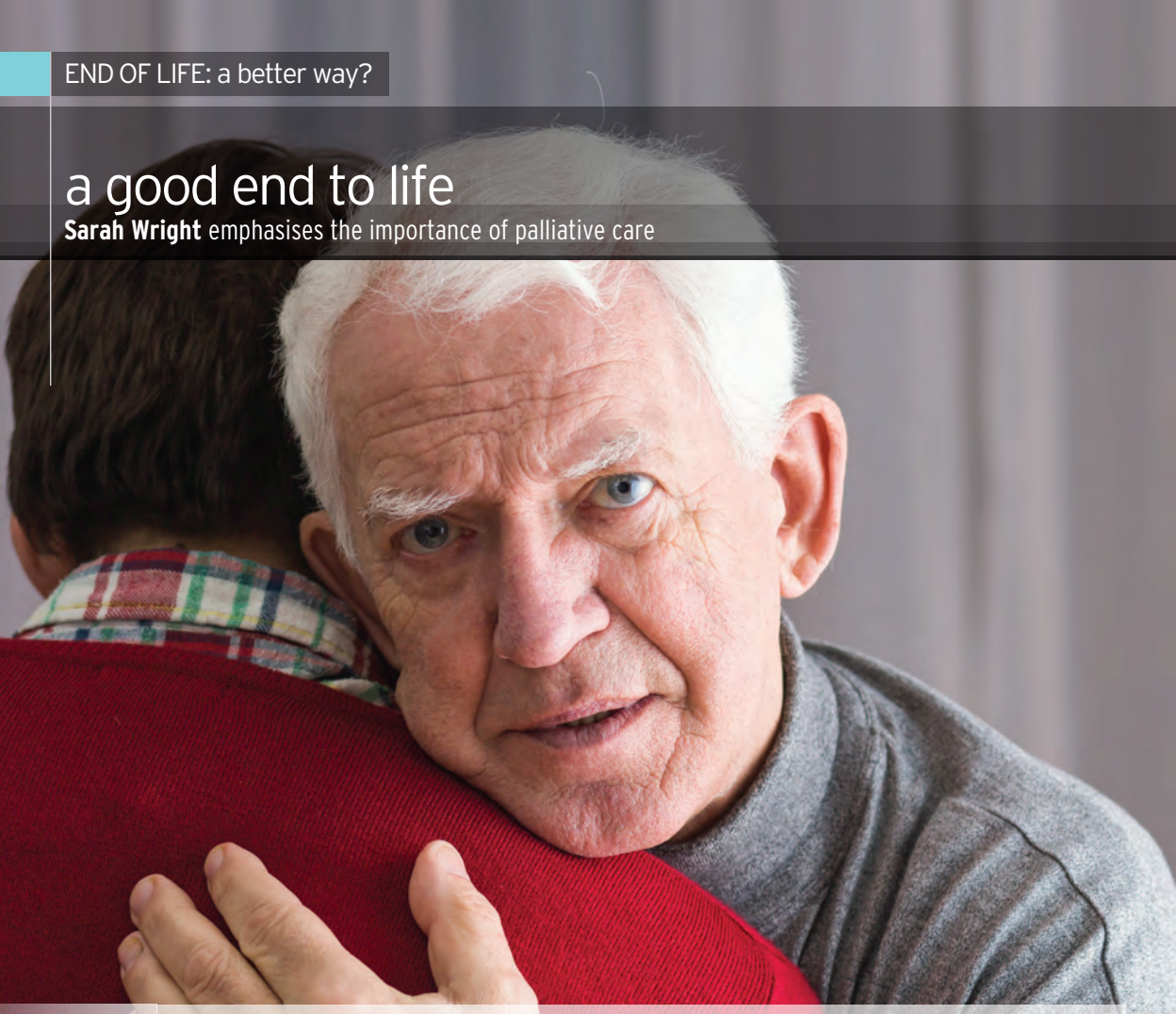
a good end to life

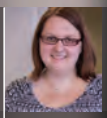
Sarah Wright emphasises the importance of palliative care



What is the first thought that comes into your head when someone says 'palliative care'? Sadness? Death? Hospices? Cancer? To me, when someone mentions palliative care I think of love, comfort and peace. Here's why.

Palliative care is defined as 'active holistic care of patients with advanced progressive illness'[1] and encompasses physical symptoms as well as psychological, social and spiritual support. The National Council for Palliative Care states that palliative care is not only provided by specialist teams in the hospital, but by 'those providing day to day care to patients'. We don't need to be experts in dosing alfentanil or levomepromazine, have a degree in counselling or be confident in sharing our faith with patients; offering simple paracetamol or an empathetic ear can massively help someone to feel more at peace.

Since qualifying three years ago and working in a number of specialties – from respiratory medicine to oncology and A&E to pancreatic surgery – not one day has passed where I haven't been in contact with someone in their last days of life. Many of our patients fear death. In today's society it is viewed as one of the worst things that can happen to you. We see people trying to delay ageing, find new ways to extend life or look for hope in being cryogenically frozen. But why do we fear death? Maybe it's leaving others behind, or regretting unfulfilled dreams, or fearing the unknown? These fears are not restricted to non-Christians. Many Christians also worry about these things. Have they truly been forgiven? What about their family? What if Christianity is a lie? But we have to trust that God is alive, he walks with us through our life and death and he has appointed our time in advance.[2] And we



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have hope. Hope in eternity with Jesus, hope that all pain will cease and hope that we'll see loved ones again. Paul writes in 2 Corinthians 4:18: 'So we fix our eyes not on what is seen, but on what is unseen, since what is seen is temporary, but what is unseen is eternal', and Jesus himself told us that he has prepared a place for us in heaven so that we can be with him.[3]

Many patients are etched into my memory and I still recall their names and diagnoses, but I especially remember their last days and hours. I remember the family that screamed at me, thinking that I'd killed their uncle; the family who refused to accept their father with metastatic prostate and bowel cancer and anuria would be unlikely to survive the night. However, I want to tell you about a patient I met as an SHO. He had necrotising pancreatitis due to alcohol excess, despite his protests that he 'didn't drink that much – only half a bottle of whisky a day and a few cans of lager'. Initially very hopeful that with careful medical management he would improve, over the course of weeks he gradually declined. He refused nutrition, became depressed and hopeless, and eventually was bedbound. As he became less lucid, we called the family to discuss the situation. That first meeting with his sisters was very difficult. With no senior members of the team available, I was left to discuss his declining health, the DNACPR decision and end of life care. Despite a rotation in oncology and watching seniors, I had never had these conversations with a family before. Reading the notes beforehand, the ward sister said to me 'You'll be fine. You've got a lovely manner. Just be honest and straight with them'. She'll never know how much those words of encouragement meant to me. And she was right too – I was fine.

The next few weeks passed in a series of ups and downs for everyone. As I had an interest in palliative care and established a rapport with the family, I was the first point of contact for the family and responsible for his end of life care. It was both terrifying and encouraging that my consultants felt I was able to manage that level of responsibility. Those few weeks taught me so much – the medications, doses, communication skills, and when to ask for specialist help. I learnt the importance of regular meetings, that taking time to review the drug doses in a syringe driver early prevents the nurses from needing to refill the driver twice because you've changed a dose late, and that checking that there is a clear weekend plan in the notes can help the ward cover immensely.

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Especially in his final couple of days, the family expressed their thanks for the care and support I was giving, and to my surprise I realised that I was providing good palliative care and making a real difference. It was such an honour to be able to demonstrate God's love, even if they didn't know that's what it was. A few days later the sister called me into her office. Usually that means something negative has happened and I need to sort it quickly, however this time it was to show me a card from the patient's family thanking the ward for everything they had done and 'thank you especially to Sarah for all her support and care'. I think it was the first time that I had received written thanks and I realised just how much of a difference good palliative care makes.

So why should we be so concerned with providing the best palliative care possible? Because Jesus would. Throughout his ministry Jesus cared for and spent time with the most vulnerable groups he encountered. He cared for Mary and Martha when they grieved for Lazarus, for the centurion

when his daughter died and for the man lowered through the ceiling by his friends. Whenever Jesus came across someone in need he cared for them – not just physical healing or comfort, but spiritual care too. In Matthew 9 Jesus encounters a paralysed man and says 'Take heart, son; your sins are forgiven'.[4] Jesus was accused of blasphemy, but he showed the man compassion and also healed him physically. Speaking to a group of followers, Jesus invites them to 'Come to me, all you who are weary and burdened, and I will give you rest'.[5] This is the essence of palliative care: providing care for those burdened with illness and giving them rest. Rest from physical symptoms, from mental anguish and spiritual pain.

So how can we show God's love to our patients and their families at the end of their lives?

1. **Take time to build a relationship.**
   Having a family's trust makes initiating challenging conversations easier, and allows you to address issues before they cause distress.
2. **Practise good communication skills.**
   It's so easy in medical school to neglect communication skills – I know I did! Take time to discuss examples of good practice with friends, and role play to improve your own skills. Watch more senior doctors and ask them how they approach difficult subjects with patients.
3. **Be aware of the specialist palliative care services within your local area.**
   This can include hospital teams, community clinics, hospices and voluntary organisations.
4. **Refer to specialist palliative care early.**
   For the patients, early referral allows time to plan for the final days, and to discuss resuscitation, syringe drivers and where they would like to die whilst they are physically and mentally strong enough.
5. **Be familiar with local prescribing guidelines and where you can find them.**
   Practise whilst you're a student or ask the doctor you're with to explain their choices.
6. **Prayer is so important in medicine.**
   Pray before meeting a family that God will help you be clear and empathetic, pray for patients and their healing, pray for families when a patient dies. When a family has known I am a Christian, offering to pray with them or for them has been welcomed gladly. Often the only thing I feel that I can do for a patient who has died is to pray for the situation.

Finally, palliative care is not just for the specialists – everyone can be involved. The last few days are sometimes the most distressing and painful times that will be experienced. Words left unspoken, family members unreconciled, debts unpaid or secret guilt can form a heavy burden adding to the weight of declining health. Of course some know this day is coming and have prepared as best they can. But for those whose health has taken an unexpected turn for the worse, they often choose to keep these burdens hidden and as medical students and doctors we feel unqualified to help. Yet, as Christians I think we have a unique opportunity to provide hope to these people, because God 'comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves receive from God'.[6] ■

REFERENCES
1. *ncpc.org.uk/palliative-care-explained*
2. Ecclesiastes 3:1-2; Psalms 139:6
3. John 14:1-4
4. Matthew 9:2
5. Matthew 11:28
6. 2 Corinthians 1:4