

## Health



◀ Dr Rachel Melsom believes in the power of technology to improve patient care

# The doctor who can help you to die comfortably at home

New technology lets those nearing the end of their lives remain at home while getting the care they need. Liz Hoggard reports

When Rachel Melsom retrained as a doctor in her 40s, she was drawn to elderly and palliative care. "They're not necessarily seen as sexy areas of medicine. It's not kids, it's not helicopters, it's not emergency rooms. But I felt we have a population who hopefully get old before they die, but the care provision doesn't always match what's available at the beginning of life." She cites her elderly aunt,

who lived alone in her 90s, having survived the loss of two fiancés in two world wars. "There was very little medical input for her when she got ill, because she'd always been very independent."

When Dr Melsom's mother got cancer in her 60s, she was desperate not to die in a hospital or hospice. "My mother wanted to be at home, which we managed to do as a family. But piecing

together the care was an experience in itself. Luckily, we had a supportive community team, where nurses would come out to ensure she was happy at home."

That experience stayed with Dr Melsom. Then, in 2024, she was made a Macmillan palliative and end-of-life care transformation lead for Sussex. Among other things, the role involved focusing on how we can use digital technology to improve care for patients and clinicians.

Before qualifying as a medic, she had trained in genetics, then worked in advertising, media and finance, which taught her to think outside the box and informed her approach.

"I wanted to make sure the patient gets the right care in the right place from the right professionals. There is a real need to 'join the dots' between all the separate but involved teams. We all need to be able to see the information the patient has shared, without needing patients to remember and repeat what they have said every time. The goal is to improve this journey," adds Dr Melsom, who also still works as a doctor for University Hospitals Sussex NHS Foundation.

As part of her research, she talked to around 200 people. "I did groups with some carers, some patients, specifically including older people, and discovered they were very happy to interact via text, because it was quick, instant and they were used to it. They were less keen on email, because it meant they had to go to find a computer, or sit down somewhere."

This inspired Dr Melsom, together with colleagues Dr Suzanne Ford-Dunn, palliative care consultant at University Hospitals Sussex, and Lisa O'Hara, nurse consultant for palliative and end-of-life care at Sussex Community NHS Foundation Trust, to design an app that allows remote monitoring of patients ("virtual care") across Sussex.

The Comfort Tracker app has been

live since last July, and the team can currently track up to 1,000 patients at home. The idea is that nursing and medical staff can have more frequent contact with patients and their loved ones, enabling them to monitor symptoms and support more people to remain at home comfortably until the end of their life.

"The patient might use the app to tell us: 'I'm a little bit more tired, I've lost my appetite', or 'I'm in slightly more pain'," explains Dr Melsom. "We can piece together a picture that gives us a much better idea of how somebody's actually doing." Carers can also update staff on new or potentially worrying symptoms, she explains. "One patient's wife reported via the app that her husband had had a coated mouth for a few months. She had assumed it was due to

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his soft-food diet. The nurses went to check his mouth and it turned out he had oral thrush, a frequently occurring condition that causes great discomfort, and reduced appetite. After taking the appropriate medication he was much more comfortable and his wife was delighted."

According to 2023 research by end-of-life charity Marie Curie, 56 per cent of us want to die at home. A familiar environment is often less stressful because we're surrounded by people and things that we love. Patients want to live full lives even if their illnesses are incurable. "Patients may have had a diagnosis that's life-limiting, but they're still up and about helping with children and grandchildren, and doing the shopping at Sainsbury's. They don't want to wait in for visits that may be moved due

to unforeseen circumstances, and want to get on with their lives in the time they have left."

But people nearing the end of their lives also face a dilemma: they need the best possible medical care, and many still experience unmanaged symptoms or unplanned hospital admissions.

In addition, some patients don't want to be reminded that they are unwell. "We had a very young lady with two young children who didn't want to see any of the nurses at home because she didn't want to have to keep explaining why they were there to the kids. She loved the Comfort Tracker, and told us: 'You can see how I am doing without visiting, and I can let you know on the app when I need you.' She had that significant time where she was able to just be a mother separate from her illness. And it was very much a joint process between the community team and the lady concerned and her partner and her children. She has since died, but it was a really well managed death."

Traditionally, changes in a patient's condition may only come to light during scheduled visits or when families reach crisis point and seek urgent help. They often don't recognise when things are changing. Patients can also under-report symptoms as they don't want to worry their loved ones, or hate to bother staff. But filling in a confidential questionnaire on the app is much easier. And if they spot that the patient is deteriorating, nurses can prepare the family. "This can help them and their family acknowledge the inevitable progress of time, and aid conversation around death and dying. Nurses can reach in to help the family understand what the signs mean, and how this impacts the patient."

"The carer may not have understood that the breathing will change or sound odd, or that they may go to sleep more. So they may try in vain to feed the patient to keep them awake."

Doctors do witness painful and upsetting scenarios at times. "Sometimes you come into a situation where you think: if only you'd phoned me last week. You see the distress on the family's face. You see the distressed patient. But now, hopefully, with the right information at the right time, we can prevent that from happening."

"One elderly female patient was being looked after at home and her daughter was filling in the app for her," continues Dr Melsom. "The nurses picked up from the dashboard that she was deteriorating, phoned them up and said, 'We're going to bring our planned visit forward.' They saw her, organised more care for her at home, and increased the frequency with which the daughter filled in the app to twice a week. They were able to highlight to the family in good time what the changes signified. The patient died peacefully at home surrounded by family, who later wrote to the team praising the Comfort Tracker."

As for the belief that older people won't manage technology, Dr Melsom has a 90-year-old patient who immediately said she'd Google more information about the app. "We underestimate that generation's ability and desire to be involved and connected. Most of us use text and WhatsApp, we do mobile banking via an app, book tickets, have loyalty cards for supermarkets, use the NHS app for repeat prescriptions and more. All these are commonplace now," she smiles. "Covid really accelerated the use of technology, as we all needed it to stay in touch."

Surrey's integrated care board will be joining Sussex soon, and the hope is that the app will be rolled out across the country. Dr Melsom is keen to stress that virtual monitoring will never be seen as a way of replacing in-person nursing care with technology, but rather as a way of giving patients the tools to feel more confident and supported, and clinicians to be better informed.

"We are all going to die at some point. Hopefully that's not going to be a traumatic experience, and over time, with any luck, we will all be in a situation where our comfort is paramount."

## DR RACHEL MELSOM'S ADVICE FOR EASING THE END OF LIFE

❖ Consider what a "good death" means or would be for you. Have you talked about what you want with your loved ones? Importantly, have you written it down clearly, so anyone who doesn't know you can also follow your wishes?

❖ Have you made a will and a power of attorney, in case they are needed unexpectedly? Hope for the best, but plan for the rest.

❖ If someone close to you is terminally ill – have you made time to listen to them, acknowledge their thoughts, and hear their wishes? Even if they currently seem well?

❖ If you or someone you are caring for is unwell, it can be hard to cope. Don't be afraid to ask for help, you are not alone.



Marie Curie have an excellent helpline, seven days a week for patients (and carers) with life-limiting illness. Macmillan also has a helpline and 24/7 online community for patients/carers of people living with cancer.

❖ If you need personal medical input, your GP should have all your medical

records and know about your health. Do see them, they should be able to refer you for other services that you might need as time progresses, including hospice input if that is needed.

❖ Don't be afraid to ask about your symptoms, what they are now and might be in the future, and don't be afraid to mention if you think something is changing. You know yourself best, so mention if you are worried.

❖ The Marie Curie website ([mariecurie.org.uk](http://mariecurie.org.uk)) also has very user-friendly information on living with or caring for a person with a terminal illness, and tips across multiple areas, including financial, clinical, planning and bereavement.