

Scenario 13 – Good access to palliative care at home

You are 92, a retired teacher with four children, six grandchildren and three great-grandchildren. You have been living alone for the past 15 years, since your second husband died, and for the past year have been totally bed-ridden following a 6-week hospital admission for a bleeding ulcer. You have carers coming in four times a day and, before the lockdown intervened, there were frequent visits from local friends, plus weekly visits from your children who all live far from you and who took it in turns to stay the weekend. In the last few weeks you have managed to have regular group video chats with them all. They understand that you are comfortable with the idea of dying at home, and recently you have talked to them about feeling ready to go.

After your admission to hospital, you signed an advance decision stating that you did not want to be resuscitated and didn't want to be admitted to hospital again. At the start of the pandemic you decide to talk to your GP to make sure that it includes Covid-19 infection and how you could be looked after at home if necessary. Your closest friend, who is much younger than you and lives nearby on her own, has made the extraordinary commitment to come and be with you, should you become seriously unwell.

Your GP phones after you contact her and you have a good discussion about the possibilities. You tell her that a friend would come and stay with you and look after you, and the care provider has said they will continue to provide care throughout. She says that if you develop symptoms, you should contact the surgery and she will arrange for some medication to be delivered, and a nurse will come and do a test for the virus. If it proves positive, she would explain to your friend what would be involved in caring for you. She also says that in an emergency, and if it's out of office hours, you can call 111 or 999 and ask to be diverted to their acute response team if you tell them that you want to stay at home.

You ask her about oxygen and she informs you that it is not appropriate to give it at home and that it is becoming apparent that in the elderly, breathlessness isn't usually a major problem. You feel very reassured and relieved. You phone your friend and tell her the news.

One day you notice that you can no longer taste your food. Then you develop a temperature and a dry cough. The nurse comes and takes a swab. The next day you hear it is positive. Your friend comes to stay and the nurse returns with some drugs and syringes, and gives instructions to your friend about when and how to use the various drugs in an emergency.

For a few days you seem fairly well but then you begin to feel muddled and restless. Your temperature is high and the cough becomes worse. Your friend applies a patch and you feel better. Your friend is there with you when you are awake, but you spend a lot of time asleep. You feel breathless if you try to do anything but are content to lie quietly and drift in and out of sleep. The days merge into each other. You have a chance to talk by video to your children, grandchildren and friends when you are lucid. If you get agitated or restless, something is rubbed into your mouth. The nurse appears a couple of times and you feel the sharp jab of a needle. Your friend sits and holds your hand and sings quietly. You remember nothing more and you slip peacefully away.