

Scenario 14 – Poor 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 contacts you by phone and explains that there aren't any special local arrangements for palliative care at home for Covid-19, but if you get symptoms to phone the dedicated 119 number to order a test. If it is positive, then let her know and she will send a prescription for some medication, just in case you should need it. If you get very ill you can ring the surgery number during office hours. After 5.30 you will have to phone 111. They will contact the out-of-hours service who can advise about any need for medication.

Two weeks later you develop symptoms and your friend comes to stay. She organises a test, which comes by post. After three days the result has failed to arrive and your friend phones the surgery. They say they will chase the result but can't send a prescription without a positive test. To begin with you just feel shivery and a bit breathless, and the carers and your friend manage your symptoms using paracetamol and a fan. One evening, you suddenly become muddled and restless. Everything looks strange and you don't know where you are. The carers have gone for the day and your friend phones 111. She explains to the person who answers that you have expressed the wish not to go to hospital. They transfer her to the out-of-hours service. This all seems to be taking a long time. When your friend gets off the phone, she tells you that they can only come out to patients who have a just-in-case medication pack, and that she will have to phone 111 again and ask for the paramedics to visit. By this time it's impossible to concentrate on what she is saying. You are trying to get out of bed because you think you are seeing monsters.

Two paramedics arrive who seem to be wearing space suits. You are panicking and feel desperately short of breath. They give you oxygen by mask and you feebly try to fight them off. Your breathlessness gets worse. They insist on taking you to hospital as they cannot stay with you and say you require medical monitoring and oxygen. Your friend tells them about the advance decision but, overwhelmed by your distress and the urgency of the situation, she can't lay her hands on it. The paramedics assure her that hospital is the best thing, and she feels she has no choice. In the rush to get you into the ambulance, she scribbles down the number of your next of kin which she finds in your address book. Unfortunately it is out of date. The current number is on your phone, which is left behind. They give you an injection and you lose consciousness.

When you come round you are in a strange place full of noise and bright lights. Everyone is completely enveloped in masks and gowns. You are immediately terrified and frantic. You are in hell. Momentarily you see your children's faces as in a dream. Grief engulfs you and you sob out loud. Another jab and you never see the light of day again.

Eventually your children track you down only to learn that you died the day before. They find it hard to forgive your friend for not taking better care of you. Your friend cannot come to terms with it either and becomes deeply depressed over the next few months. Fortunately, if she does catch the virus, she is not aware of it as she never gets any symptoms.