

Looking after mother

Ros Coward



Mum had been told she would be staying in hospital for "about a week" while they put her on warfarin and sorted out her blood. But when I visit on Monday afternoon, I find her sitting on her bed with her coat on and her trademark rucksack packed beside her. "Look," she says to the staff nurse standing by the bed, "we don't need transport after all. Here's my daughter."

I'm flabbergasted. "You weren't really going to send Mum home alone without contacting anyone were you?"

"She doesn't need to be in hospital now," answers the nurse.

I persist. "Did you try to contact me?"

"Yes," she says, "but the number wasn't in use." My old number again. Which would have been provided by Mum. I begin to bristle. I bet they've lost the notes ... again.

I try to stay focused. "What about the new medication? The warfarin? Isn't it a bit complicated? How is she supposed to have it?" Previously she had been having heparin administered by a district nurse, by injection.

"We're making up the medicine now. All the instructions are in the yellow book."

I pick up the "yellow book" lying on the bed and thumb through it. It's full of dire warnings and I notice there's a date in four days time when she's meant to "come to the hospital" to have the medicine adjusted. I feel myself panicking. Clearly Mum has been signed up to another demanding regime that we are meant to administer but know little about.

"Now look here," I say. "Surely you can't just chuck her out. You know she lives on her own. And has dementia." A rather supercilious doctor comes over sensing trouble. I'm gabbling but that's

because I'm panicking. "Someone comes in to prompt medication in the morning but we don't have anything regular set up for the evenings."

"Well you can give them to her in the morning," he says.

"No you can't," says the staff nurse. Great. If they don't know how to do it, what makes them think Mum will?

"You can't just send her out. You haven't set anything up for this to be administered. Her family can't do it." I am aware I sound like the disagreeable daughter who won't look after her old mum, but this is not good. "If you're changing her regime and it has implications for her care, why hasn't anyone come for her care assessment?"

They both stare at me. I'm not giving in. I stare back.

No one seems to be coordinating her care. They seem to have abandoned the great quest to find the cause of the embolism; a quest which probably caused bleeding and led to all the recent emergencies. Now, suddenly, she's "fine", clogging up the beds in fact. Her treatment has turned into a joke. Except the usual definition of a joke is that it's funny.

"I'm going to find out about this," says the staff nurse, going off looking guilty.

"Aren't I coming home?" says Mum, pathetically.

"I feel bad about that," I say.

"No, you're right," says Mum's friend in the bed opposite, who used to be a nurse. "Warfarin's dangerous. The pills have different colours. So

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one week it might be two pink and one white, then they adjust it. If you get it wrong she'll bleed to death."

The nurse comes back. "We can't let your mother out before the social worker has seen her," she says officiously, as if I have been trying to force Mum home against their will. "And the social worker can't come up to the ward until Thursday."

"Thursday!" I know the hospital is a maze, but surely even a social worker wouldn't take three days to find the ward.

Strangely, the social worker arrives the next day and there follow three long days of negotiations with different arms of the "caring" professions, where we try to persuade them that taking Mum to the hospital every week (along with all her other appointments) is not viable and instructions such as "carry your yellow booklet with you at all times" and "take the new combination of pills every tea time" are pointless for someone with dementia. Eventually, we reach agreement: district nurses will come to Mum's home to do blood checks and the carers agree to extra hours in the evening. When I mention this is medical care and not social care so we shouldn't have to pay for it, everyone becomes evasive. I don't press the point.

I drop by one evening and find the carer randomly opening pill boxes looking for instructions. It feels pretty risky. But what can we do? I'm talking to myself when I say, "I hope these doctors know what they're doing."

But Mum hears. "They think they're gods and we're just old rubbish."

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Next week Chris Cleave

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What do you think?" I whisper to Mum once the daycare centre manager

goes out of the room. "It seems all right," she says. The manager comes back with a cup of coffee for each of us. I gulp mine down, but Mum barely touches hers. "Too much sugar," she whispers to me.

"You do really like it here, don't you?" I ask again.

"It's fine," she says. But she says it as if this is nothing to do with her, rather than a place we are checking out for her.

It does seem fine; much smaller than I expected but also, in many ways, much better. There's nothing here of urine smells or miserable old people slumped neglected in their chairs. This is all clean cheeriness. There's a dining room with an appetising-looking menu on the blackboard. The "clients" come and go between rooms at will. A new batch arrives by the morning bus and are settled in to have tea and toast. There's a pretty little garden outside with big trees.

"It's lovely here," says a chatty lady. "I come every day. I call the staff 'angels'. We go on outings."

"Where do you go?" I ask.

"Oh, pub lunches and things." Perhaps this is why the doctor has always insisted that this place might suit Mum, adding that he wants to reserve a place here for himself.

In spite of all this, it's not the sort of place – organised, dull, elderly – the Mum of old would have looked at. Even last week she was in defiant mood. "She refused point blank to go to the day centre when I suggested it," the community nurse told me.

I've been delaying this visit, partly for Mum's sake but also I've been

dreading the memories it might stir up. My father ended up in such a place, although then, 20 years ago, the provision was different. He went to a centre that offered daycare and residential care and he had to have both at various times. There was a period when I couldn't bear to witness the interaction between my mother and father and took to visiting him at his care centre rather than at home. Although Mum was considerably younger than my father, she couldn't cope with his illness and ageing. In spite of this, one of the last things he said to me was, "You will look after Mum, won't you?"

Is it looking after her to even contemplate sending her to a place such as this? How could it possibly be OK for someone with such a strong sense of independence to find herself collected by bus to join a room full of old people doing "activities"?

But it's precisely Mum's ingrained habits of independence that are now creating the problems. In the past, they have served her well. Instead of sitting watching television all day, she gets up and heads out to the pub or cafe, getting on the first bus that goes past. She knows the London public transport system inside out, remembering it better than many things in her life. Instead of accepting carers' offers to make her a sandwich, she insists on

frying something for herself. Now these habits are all getting too risky. Last week, there was the usual call from Wandsworth Telecare that the flat was full of smoke again. And another mini-crisis when she didn't come home until 9pm, explaining vaguely that she'd been "up town". Now, having to take the warfarin every evening, it's expedient that she's at home to have it. Anyway, she seems to be finding it all hard going at the moment. "I'm a dead duck," she says frequently, or her favourite, "I'm the Wreck of the Hesperus."

These are all the signs that have been telling us, for a while now, that we are moving into a new phase, one where we really do have to sort out something more than

the current piecemeal arrangements. What would be best? Probably, if Mum would accept it, live-in care. Friends who have been able to arrange this for their elderly parents say it radically transforms their and their parents' lives. But these are options mainly open to the well-off. We could only afford it for a bit. And then what? Would Mum have to sell her flat and go into care? "There are several stops before you reach that point," says the community nurse, suggesting a live-in volunteer from a charity. "But let's try the daycare centre first."

I take a deep breath and ring the nurse up and tell him she said the centre was "fine". Later that day, he rings back. "I've told them she'll come two days next week." I put the phone down, slowly feeling sick. It feels like a betrayal.

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