

Dying at home: a few things the family should know

For forty years, Daily Information has been committed to keeping people informed of useful things for living. The founder having died last week, we continue this tradition with some things it helps to know if you or a family member are dying. As soon as John Rose was diagnosed with advanced cancer, in May 2004, he and I (his wife) and our daughter were all determined he should live the rest of his life in his own surroundings if at all possible. She and I are both thankful that we were able – and enabled – to see this through, and he died not only in his own home, but in his own chair.

There are however, some fruits of this experience which I should like to share with others – forewarned is forearmed.

1. During diagnosis you will probably be sent to various different departments at the hospital. If you know there is nothing that can be done to prolong life, make sure that you get an early referral to Sobell House Hospice. They are very skilled in improving the quality of life for as long as possible, as well as in supporting everyone towards the end. Think of yourself as the consumer: ask whatever questions you want to ask; insist on straight answers if you can take them.
2. Once it is clear what you are dealing with, you will need all the resources you can lay hands on – resources of time, and of money. With all the good will in the world, dying at home is bound to be expensive on both counts. I was fortunate in that I work from home, so was able to keep a modicum of work going; my daughter deferred her degree for a year.
3. You will need all the resilience you can muster to persuade people that you are giving this, and nothing else, priority for as long as it lasts. Be quite sure that this is what you want to do. Make it your bottom line, and negotiate from that position and that position only.
4. Once a person has been diagnosed as terminally ill, you are entitled to £58.50 a week. It may not sound much, but it might make all the difference to, for example, being able to get out of the house for an hour or two. However, you are only entitled to this from the time you make the claim. It can be done without bothering the patient under something called ‘special rules’ – ask your GP, who has to do most of the paperwork.
5. Also, once a person needs full time nursing at home, you are entitled to night cover plus 2.5 hours of carer time, spread over four visits. You do not have to pay for this. If you want to use more qualified help, or help over longer periods, you can pay the difference.
6. Do not reject any help that is offered. We were superbly supported by the district nurses and the Marie Curie Foundation. It may seem difficult at first to have people coming into your home whom you don’t know, but these are people who are completely geared to homes, families, and their ways, and no-one who came to us was in any way intrusive. They were sensitive, skilled, and adaptable.
7. All kinds of equipment is available. You can have a hospital bed in your home to make it easier to nurse someone who has to be in bed. You can have a hoist for lifting. Do not write out cheques you will not be able to meet when it

- comes to using your back muscles! If there is anything that might help, ask, though in our case, the district nurses anticipated every need.
8. Be aware that nothing stands still. Plan ahead where possible, because as soon as you have adapted to one stage of the process, the next will be upon you. Note that private nursing agencies do not operate seven days a week – they may answer the phone on a weekend, but are unlikely to provide you with any cover until Monday.
 9. When it comes to the death itself, first call a doctor to certify it, and then – straight away – the funeral director. They will come to the house once the death has been certified by the doctor, but the more time you give them to get there the better.
 10. Start straight away – or get someone to do it for you – on the funeral arrangements. You will need to know whether you want church or otherwise, burial or cremation. Think about what you want to happen afterwards. Find someone you are really at home with to be with you for the evening after the funeral – in my experience that is the darkest hour. Remember the funeral has to be planned quickly, so that you may not be able to do all that you want, but you can always have some other kind of memorial event later on.
 11. Be prepared for the fact that if the hospital (in the form of equipment) has come to you, rather than you to the hospital, you cannot walk away from it. Although (this is my one complaint but it is a very serious one) beds, hoists etc can be delivered almost straight away when needed, they do not expect to collect them from your home for up to two weeks after the death.
 12. Be aware you are probably in shock, however much you expected the death. Expect to catch every germ going: stress boosts the immune system, but as soon as you start to relax you are a sitting duck. Use being ill to get some rest. Expect to have a lot of adrenalin until the funeral and then make arrangements to be as exhausted as you need to be.
 13. Death notices in the national papers are expensive, and you cannot phone them at weekends. Once you do get through, they are charming and helpful. We had eight lines of announcement and The Independent was the best value at £56 plus VAT. Guardian: £78.14, and The Times £235, both including VAT, so ask before you commit yourself.

And finally: be trusting, be grateful, be receptive – there are some marvellous people out there – but if something goes wrong, do not be prepared to compromise. Hopefully most newly bereaved people will not face what happened to me. Having arranged the funeral on a Friday, and started informing everyone including the national papers, I was told on the Monday that it would have to be a different day because of pressure at the cemetery. You do not have to put up with this. There are ways round it if you simply sit it out, and refuse to budge.

May his memory be eternal!

Jessica Rose