

End-of-life care at home out of hours: think 3 am!

Laura-Jayne Wilcock is a nurse and currently leads the NHS out-of-hours service for Care UK in South West London. Here are her thoughts on what you, as a clinician planning the home discharge of a patient at the end of life, need to bear in mind

Picture the scene: it is 3 am, a time when it seems that the whole world is asleep and no one is around to help. One of your patients, who was referred to your team for end-of-life care, has recently been discharged home, as this is their preferred place of care. They are being looked after by a family member – a spouse, a child or maybe a sibling. That night, they experience a rapid deterioration in their overall condition. Their relative is, understandably, anxious and unsure what to do. Their one option is to call for help.

As it happens, they live in an area where there is no direct access to specialist palliative care services out of hours – in England, the NHS is under increasing financial strain and is ever tightening the purse strings. So the relative will dial either 999, and their call will likely be handled by the ambulance service, or 111 (the NHS 24/7 non-emergency service that offers medical support), in which case their call will be managed by that service.

As a nurse who has worked for NHS 111, I have spoken over the phone to many patients, families and carers experiencing 3 am anxiety and looking for help. When I work out how best to help them, there is one factor that will either help or hinder me, and this is how well care has been planned. Is there a care plan that will give me quick access

Key points

- ▶ When planning the home discharge of a patient in their last weeks or days of life, professionals must put themselves in the shoes of the urgent-care doctor or nurse who will manage that patient's care in case of a deterioration during the out-of-hours period.
- ▶ Good end-of-life care out-of-hours requires that the patient's care has been thoroughly thought through, that the family has been prepared for what is likely to happen, and that there is an up-to-date digital care plan and ready access to emergency medication.

Box 1. A few websites helpful for patients/families to cope with the dying phase and death

- Macmillan Cancer Support: www.macmillan.org.uk/information-and-support/coping/at-the-end-of-life/dealing-with-the-news
- Dying Matters: www.dyingmatters.org/overview/need-support
- Good Life, Good Death, Good Grief: www.goodlifedeathgrief.org.uk/content/support

to reliable information? Does the family know what to expect and what to do? Is there a supply of essential medications in the home?

An up-to-date and comprehensive digital care plan

In my work, supporting patients and families can be like trying to do a big jigsaw puzzle with pieces missing. At worst, all we have is the information the patient and/or family are able to give us. At best, we have access to the patient's summary care record, or their file on an electronic palliative care co-ordination system (EPaCCS), or their urgent care plan on Coordinate My Care (CMC). But what is truly vital though is the quality of the information.

One key aspect is whether or not the care plan is up to date. An out-of-date care plan can cause huge levels of distress to all involved. It may cause delays in accessing the right information, it may force patients and families to repeat difficult stories, it might lead to interventions that the patient would have preferred to avoid – for example, an admission to hospital. A thorough, up-to-date plan will ensure that the visiting doctor or nurse can quickly find out everything they need to

know. The easiest way to keep a care plan up to date is to use a digital format. GPs from the out-of-hours service can access CMC on a secure tablet, for example, as long as there is a good internet connection. They can also use special patient notes that have been added to the out-of-hours platform by the patient's GP.

Key information that must feature in the care plan are the patient's contacts, both personal and of health- and social care professionals. Who needs to know what is happening? Who to call to obtain extra help?

A family prepared for what is likely to happen

Recently I answered a call in the middle of the night from the daughter of a palliative care patient: her mother had just died, she was on her own and scared. She hadn't been told that her mother might die so soon and didn't know what to do. She said that the one thing that would have comforted and empowered her would have been more information about what to do in these circumstances.

Death is still a taboo subject and many people, including health professionals, simply don't know how to talk about it, so families are not prepared for it, including on a purely practical level. GPs, and clinicians in general, need to have more open discussions with families about what to expect in the last few days and hours of life, what to do when death is near, what to do afterwards, and so on. This will not necessarily make death and its aftermath smooth and easy, but it will mean people are better prepared for these potentially traumatic times – as opposed to having to discuss practicalities at the worst of moments with a healthcare professional they've never seen before. Box 1 lists a few useful websites that you can direct patients and families to.

Ready access to emergency medications and equipment

Our urgent-care doctors and nurses do their best to ensure patients receive fast and efficient care, but this can be challenging if simple palliative care equipment and essential medicines are not readily available in the patient's home. Patients dying at home need to be equipped with ready-to-use emergency drugs (with a syringe pump if needed), an up-to-date drug chart, and equipment such as a commode in case they get weaker in the course of the night or over the weekend.

Remember that, once they are back home, your patients might need help from a nurse or doctor they've never seen before



A well kitted emergency medication box in the home may seem like a simple measure. But in the out-of-hours period it can make a big difference. When there is only one pharmacy open in the whole of London, having to collect or having to send families to collect medications adds unnecessary stress and complexity to an already difficult situation.

Concluding thoughts

The 'in-hours' period is only between 9 am and 5 pm, or thereabouts, while the out-of-hours period represents all the rest; that is, approximately two thirds of the time. We also know that the same number of people die every hour, whether this is during the day or at night, during the week or at the weekend. Therefore, out of all people who die, two thirds die during the out-of-hours period.

When end-of-life care is done well out of hours, it can be of great benefit to all. Our staff can provide comfort, compassion and great care, despite the fact that they have just met the patient and their family, and provided care has been thoroughly thought through and well prepared.

So when you're planning the discharge of a patient in their last weeks or days of life who is going home, put yourself in the shoes of the doctor or nurse who has never met them but will manage their care at 3 am in case of a sudden deterioration. Think of that phone call in the middle of the night. Think 3 am! ■

Declaration of interest

The author has worked for Coordinate My Care in the past.

Laura-Jayne Wilcock, Service Delivery Manager, South West London Out of Hours Service, Care UK

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website: www.ejpc.eu.com
email: edit@hayward.co.uk