Hospice at Home
TOOLKIT

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One Page Summary for:

Supporting Family and Friends Caring at Home

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Research into hospice at home services

Hospice at Home services support people towards the end of their life, to live at home for as long as possible and to die at home if that is their preference. We undertook a research project (2017-2020) to understand how to get the best performance from hospice at home (HAH) services in England, to optimise patient care and outcomes. We carried out a national survey and then looked into 12 services around the country in detail. We recruited 339 patients and their family/friend carers and interviewed 85 professionals (frontline staff, managers, senior decision makers in the hospice and commissioners).

What did the research show?

- Almost all Hospice at home services provided personal care, psychological and social support and symptom management (not all provided this 24/7); on average for 1 week – 2 months from referral.
- Hospice at home services overall provided care that was likely to deliver ‘a good death’ and 73% of patients died in their preferred place. Patients supported by hospice at home services were much less likely to die in hospital than the general population (9% vs 46% [2017 data]).

Key elements of Hospice at Home support linked with the best outcomes for carers were:

1

Preparedness

How the patient and their friend/family carer, as a unit in the home, feel about dying at home and respond to the challenge of this situation will be key to achieving death at home.

2

Addressing the needs of the carer

Staff from a range of disciplines need to assess and respond to the wellbeing and needs of the carer as well as the patient.

3

Expectations

The HAH service fully informs the carer about what might happen in terms of the trajectory of illness and the increasing burden of caring over time. Carers will then know what to expect and can rapidly recognise a change in caring situation from control to crisis.

4

Support for caring

The patient and carer choices are affirmed and supported whenever possible, giving the carer and the patient an increased sense of control.

Negotiations take place with the carer about how much they are happy to take on and the carer receives skills training.

The carer is given permission to do caring tasks that are traditionally seen as ‘professional’ tasks. Their confidence will also depend on knowing how to get help or advice when needed 24/7.

5

Partnership

A full assessment of care needs including the whole family/care unit is required. The HAH service should negotiate a partnership with the carer, including clarity about what can and cannot be provided, and recognition of what the patient–carer dyad wants over time.

6

Bereavement

In bereavement, there may be short- or long-term consequences of caring on the carer’s mental and physical health. Many carers would prefer bereavement follow up from HAH staff they already know. Some carers may need more bereavement support from experts.