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One Page Summary for:

Hospice at Home Managers and Leaders

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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, psychosocial 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 admitted to hospice at home services were much less likely to die in hospital than the general population (9% vs 46% [2017 data]).
- All HAH services offered care which was highly rated by family/friend carers.

Key markers linked with the best outcomes for patients and families were:

1 Sustainability

HAH may enable sustainability of their service if they proactively seek control over available statutory funding, engage with the wider health and social care environment and, if a charitable organisation, undertake income generation from a range of sources. To recruit and retain staff to deliver the care that patients need, a HAH service requires a reputation for excellence and investing in staff development.

2 Volunteers

Volunteers are effectively recruited, trained and managed, including clear responsibilities, support and lines of reporting. HAH services may benefit from (re)considering what roles volunteers could have in HAH. HAH services may take a different approach to some aspects of volunteering, along the lines of the "Compassionate Communities" model, in which volunteers act as good neighbours.

3 Integration & Coordination

The HAH service works in a coordinated and effective way with other service providers, at organisational level and on the ground.
If patients and carers are provided and updated with information, including who and how to contact professionals, then the chances of them receiving a seamless service and continuity of care with consistent information increase.

4 Marketing and referral

To increase referrals in general, and in particular of those who are poorly represented in hospice services, HAH needs to actively market its service to professionals and the public through clinical and public engagement. Referral systems need to be as simple as possible and not require complex transfer of information.

5 Skills & Ethos of Care Providers

To add value to the whole system of care, HAH services need to provide expert knowledge and skills in EOLC with a suitable ethos to support this care. This is enabled by experienced staff who have spent a significant proportion of their time in EOLC so that patients and families trust them. Staff at all levels are suitably trained, including relevant communication skills.

6 Support directed at the patient–carer dyad

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