

In this article...

- Needs carers may have when a loved one is approaching the end of life
- Details of a pilot initiative to improve the experience of carers in three care settings
- How a collaborative approach can improve support for carers at this time

Walking the Walk: support for carers of a loved one at the end of life



Key points

Support provided to carers can help everyone better manage the period at the end of life

The Walking the Walk initiative was first developed to help acute hospitals understand how to meet carers' needs

A pilot initiative shows this approach translates well into other settings such as care homes, community hospitals and GP practices

Evaluation suggests that the initiative has renewed participants' motivation to better support carers

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Abstract When a carer's loved one is at the end of life, the carer's needs can often be overlooked despite this being a distressing time. Walking the Walk is an initiative first developed to learn how to better meet the needs of carers in the acute hospital setting; this article describes a pilot adapting it for use in care homes, GP practices and community hospitals. The project has received overwhelmingly positive evaluation responses, with participants reporting a renewed motivation to better support and cater to the needs of carers.

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Dealing with death may become routine for many working nurses but it is often uncharted territory for carers, and can be a time of profound distress, grief and bewilderment. The carer's needs can very easily and unintentionally be overlooked (Hardy, 2018; Payne et al, 2010).

In recent years, a great deal of work has been done at national level to promote the role and needs of carers in end-of-life care; this was first outlined in the National Palliative and End of Life Care Partnership's (2015) ambitions framework and the Dafodil Standards for GP practices (Bit.ly/RCGPMCDaffodil). There is increasing evidence that the experience of the carer has a huge impact on how they cope with their bereavement, so support systems should take into account their needs as well as those of the patient (World Health Organization, 2020; Ewing et al, 2018).

The Walking the Walk initiative was first used in acute hospitals to help staff understand how to best support carers. Developed by a small team of carers and health professionals, it was born out of the

need to improve the experience of distressed and grieving carers as their loved ones were approaching the end of life.

For this pilot project, Walking the Walk was adapted for use in care homes, community ward hospitals and GP practices. Funded by NHS England, the project studied six sites (two in each care setting) from a large clinical commissioning group that were recruited by invitation. There was a focus on using the language of improvement, rather than inspection, to encourage open, collaborative discussions between the Walking the Walk team and the host sites. The project has received overwhelmingly positive evaluation responses, with participants reporting a renewed motivation to better support and cater to the needs of carers.

This article outlines the pilot initiative and why it is of value to all nurses involved in end-of-life care in particular.

Our approach

Walking the Walk is a quality improvement initiative that was initially designed to improve the experiences of carers whose

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loved one is approaching the end of life and may die in hospital. Using an experience-based approach adapted from two seminal programmes – the NHS’s 15 Steps Challenge ([Bit.ly/NHS15Steps](https://bit.ly/NHS15Steps)) and the King’s Fund’s Enhancing the Healing Environments programme ([Bit.ly/KFHealingEnv](https://bit.ly/KFHealingEnv)) – a small team of experienced nurses and carers use evidence and experience to feed back on:

- What is good care provision?
- What improvements may need to be considered?

Feedback is presented verbally and in a report to the host organisation for them to use as they wish.

Method

In the early phase, a People in Partnership Group, comprising members of the public with end-of-life care experience, hosted by Hospice UK, was instrumental in testing the process. The experiences of bereaved carers were central to each stage of the design. Questions were asked that subsequently informed the initiative such as:

- What matters to you?
- What helped you get through that time in your life?
- What would have helped had it been available?

We aimed to capture key environmental features and processes of care from the ‘front door’ to the mortuary. These ideas were then grouped into four themes:

- Environment;
- Access to care and support;
- Involvement in care of loved ones;
- Care after death and bereavement care.

As Walking the Walk was originally designed for acute hospital settings, the methodology was adapted for use in care homes, community hospitals and GP practices using a quality-improvement approach of rapid cycles of change. Existing resources in those settings – for example the Care Quality Commission’s key lines of enquiry ([Bit.ly/CQCKLOE](https://bit.ly/CQCKLOE)) and the Daffodil Standards for primary care were also incorporated. To test this adapted approach, several organisations were asked to participate in the project.

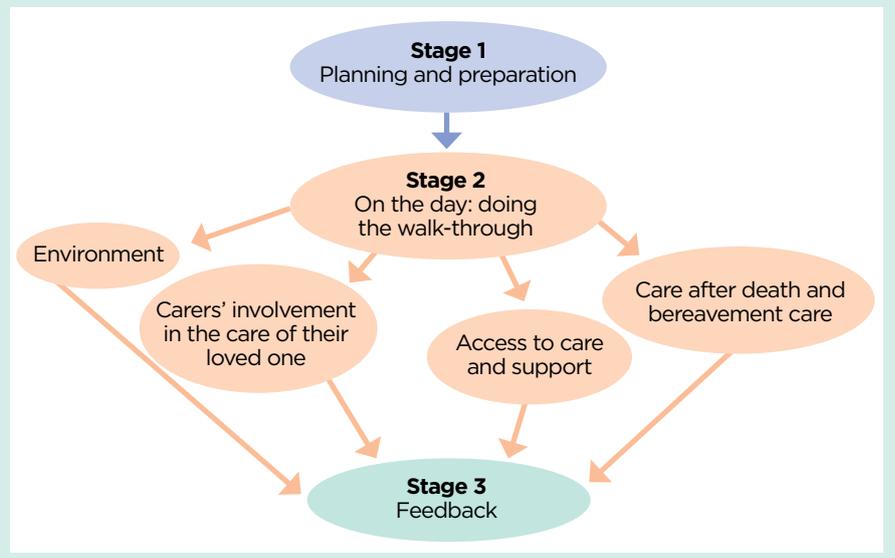
There were three stages to this process:

- Planning and preparation;
- Undertaking a walk-through of each participating organisation;
- Feedback (Fig 1).

Stage 1: planning and preparation

Before the pilot, the Walking the Walk team liaised with the host participants to emphasise the project’s focus on

Fig 1. Stages of the Walking the Walk approach



improvement rather than inspection, and discuss the process and practicalities of the visit. This included briefing key staff who would be invited to speak with the team on the day and gaining permission to take photographs of the environment.

Stage 2: doing the walk-through

The visiting Walking the Walk team would visit public spaces, unescorted by any host organisation team member, using the resources such as signage, volunteers and relevant staff as if they were a member of the public wanting to find a location or seek advice. When visiting clinical areas, they were escorted by a host team member who would ensure it was appropriate for them to do so.

On the walk-through, the team focused on four main domains, as detailed below. The walk-throughs were focused on anything about the dignity and respect of carers and their loved ones that was pertinent to that care setting.

Environment

- Public areas:
 - Review the accessibility of the car park and public transport options;
 - Consider whether there was clear signage to areas important to carers;
 - Assess the welcoming nature of the reception area and corridors;
 - Study the information readily available to carers on noticeboards;
 - Check facilities, catering options and the like.
- Care areas – the team should:
 - Consider what the environment felt/smelt like;

- Assess the carers’ access to staff and support, and whether they can stay overnight;
- Study logistics on how, for example, the deceased are transported to the mortuary.

Access to help and support

- Check the provision of information in the chapel and multifaith spaces, and information about contacting the chaplaincy team;
- Assess whether the space was inviting (temperature, lighting), and there was access to wifi, quiet spaces, clear signage and parking;
- Consider how available and proactive staff were in speaking with the carer to offer updates, follow up on previous conversations and see how they are coping. Ascertain the range of support offered around issues such as dealing with grief, financial or legal advice, and practical help with care matters after death;
- Check ease of access to appropriate resources, be they online or in print.

Involvement in care of loved ones

This is an incredibly important aspect to get right: if done well, it gives much comfort and peace to carers after the death of their loved one. It is not uncommon for carers to focus completely on achieving the best possible care for their loved one and not attend to their own needs (Ates et al, 2018). Before the admission, a spouse or a relative may be the primary carer and some may have been doing this for years. It may be important for the carer to find a

way to continue this special role in some way when their loved one is in a care facility; this needs to be explored with sensitivity. Perhaps they are exhausted but still keen to care. What involvement would they like? What does the dying person wish for?

Care after death and bereavement care

- Discuss with department staff in the bereavement office/suite and the viewing room/mortuary about how the deceased is cared for and presented, as well as the aesthetics of the room and attention to cultural sensitivities;
- Consider how long it takes to collect the death certificate, and the ability to have a positive informative meeting with the medical examiner, as well as access to clear local information about registering a death, bereavement support and how to retrieve a loved one's possessions.

Stage 3: feedback

Feedback is couched in the language of support and quality improvement, not regulation and inspection. The intention is to create a safe environment that lends itself to an honest, interactive feedback session.

The Walking the Walk team should share their key observations and insights, and offer suggestions (Box 1), recounting what was good and what could be considered for improvement. This feedback, which is supported by photographs, forms the basis of a discussion with the host organisation; from that, potential proposals for improvement are considered. A written report follows, which is reviewed by the host for any corrections, before being signed off by both parties.

Box 1. Examples of how to support the carer

- Provide facilities that enable carers to stay with their loved one and be valued as an important person to the patient
- Ensure carers are supported to provide care
- Provide a space for carers to rest and have access to affordable food and drinks, and wifi
- Offer access to a trusted and reliable contact, plus key information
- Display clocks that work
- After their loved one's death, provide information and guidance on what to do and where to get help

Evaluation and discussion

Evaluation was captured on the day via questions as part of the feedback session; these explored issues including:

- The host team's experience of pre-visit preparation and contact;
- Their experience of the actual process;
- Its value for them in eliciting new insight and information.

Host organisations are contacted 1-2 weeks after receiving the report to ascertain: their intentions on how it will be used, feedback from staff involved in the visit, and their next steps.

On-the-day and post-visit feedback was consistently positive from all host organisations. It was clear that all three phases were key to a good overall experience:

- Stage 1: feedback was about the importance of building a good rapport with the host organisation's team and agreeing the plan for the walk-through;
- Stage 2: it was key for the Walking the Walk team to conduct the walk-through in a supportive and discrete manner, bearing in mind the need to be flexible and respecting the fact that they are often visiting a busy, dynamic clinical working environment and may need to revisit later;
- Stage 3: the Walking the Walk team's aimed to celebrate what they had found that was good and innovative, as well as suggesting features of the environment or practice that the organisation might wish to change, and what was well received. Without exception, the host organisations found hearing directly from the carers on the Walking the Walk team immensely powerful and compelling.

Several host organisations have shared what steps they have taken as a result of

the walk-through and have asked to be put in contact with other organisations to learn and introduce improvements to their approaches to care.

Below is a quotation from a ward sister in a community hospital, who had taken part in the initiative:

"Thank you for taking the time with this comprehensive report. It has proved very helpful having the insight from an outside point of view and has given me many opportunities to improve the experience for our carers. I did not realise the hospital does not 'advertise' its service to our dying patient and bereaved families. I did not realise our website is so unclear about our services. Your photos remind me how long our corridors are. More chairs are definitely required!"

In the future, ideally, the Walking the Walk team would revisit the sites to assess the impact of the exercise several months later. A virtual community is worth considering to enable sharing of good practice, ideas and exploring solutions to challenges encountered in this area of care.

Conclusion

This pilot showed the Walking the Walk approach that was developed for use in acute hospitals can be adapted for other care settings. The host organisations that saw the greatest impact had placed value on the independence and expertise of the visiting team.

The Walking the Walk approach appears to offer a rich source of learning on how to improve the carer experience and can be used alongside other data such as audit, user feedback and staff experience. The feedback from all care settings suggests this approach is highly adaptable and offers a fresh perspective. **NT**

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