Developing an end of life care support pathway

Anna Jackson and Ruth Dixon describe how specialist provision can assist the people caring for patients who are in the final stages of life

Abstract

People looking after family members and friends in their final remaining weeks of life have needs that must be recognised and accommodated. A service improvement pilot assessed the physical, emotional, social and financial needs of carers, examined gaps in existing provision and looked at how partnerships could be built.

Keywords
End of life; palliative care; carer needs; care pathway

SOMEBE WHERE IN the UK, someone is acting as an unpaid carer to a loved one in the final stages of their life. Faced with an ageing population, the country is going to see an ever-increasing number of people looking after family and friends in their remaining months, weeks, days and hours of life. They have their own needs, but what are these?

Nurses from community and acute settings have been closely involved in a service improvement pilot exploring ways in which the physical, emotional, social and financial needs of carers at such a traumatic time can be met. The pilot was co-ordinated by the charity the Carers’ Resource, which has offered support and guidance to more than 15,000 carers across north and west Yorkshire for more than a decade. The charity secured six months’ funding for the pilot through Yorkshire and the Humber Improvement Partnership’s Carers’ Innovation Fund. In partnership with existing health and social care teams working on the end of life (EOL) pathways, the Carers’ Resource piloted and evaluated provision of specialist support for carers of those nearing the end of life in hospital and at home.

The pilot’s four overriding aims were to:

- Explore ways of embedding carer support into secondary and community care services with an EOL focus.
- Build partnerships with health and social care professionals in this field to share expertise.
- Begin to develop a carer pathway to ensure the appropriate type of support is offered at the best times and in the best ways and locations.
- Develop an end of life care support pathway

The pilot involved hospital palliative care, hospital discharge and care of the elderly wards in Bradford Royal Infirmary (BRI) and Airedale General Hospitals (AGH). Additionally, local hospices, including Marie Curie in Bradford, plus the community teams and some specialist clinics from AGH provided placement opportunities for our carer support officers (CSO).

Almost 100 carers from across the Bradford and Craven areas of the county – a diverse population encompassing both inner-city and rural communities – were interviewed to gain an insight into unmet needs and gaps in available support. Drawing on the experiences of these carers, and feedback from health professionals, a pathway has been developed mapping out what extra support would be valuable, and when.

The existing EOL pathway recommends that carer and family support and information is a cross-cutting theme, but gives little guidance. As a result of this pilot, a carer support pathway (Figure 1) has been devised to suggest how this could be accomplished alongside the patient pathway, what form support could take and how to achieve integrated care for carers and patients.

Carer information is very different from patient information. It should examine and explain how progression of a condition, medications and so on will affect the life of the caring family. The carer perspective is critical to every stage of the pathway and should always be produced with support from, or in partnership with, a carer specialist agency. Whenever possible, it should be disseminated to...
Early identification and referral by health and social care professional to increase take-up of support. As patients are entered onto the EOL register, the carer’s details are also recorded but little is done with them. An automated electronic referral should be possible, direct to a carer support agency (with a choice to ‘opt out’ rather than the requirement only not to ‘opt in’), which will ensure sensitive first contact is made. Anyone making the diagnosis and breaking the news to a patient that they are entering the last year of their life should be responsible for ensuring that at least the primary carer is identified, acknowledged and referred for support, irrespective of who or where this is happening – for example, the GP practice, in hospital, in the community.

Inclusion in care planning and assessment
Recognition of carers as expert partners in care by the professionals involved is essential. The inclusion of carers in discharge planning is likely to make the discharge safer and reduce the chance of readmission to hospital.
Carers will be vital to sustaining care throughout the EOL journey and are pivotal in deciding what and how this needs to happen. CSOs who have picked up the referral should be available to enable important discussions about care planning or discharge, and their own lives and commitments. They can ensure the carer fully understands the process and is able to clearly and honestly express their views, concerns and level of capacity to provide care (see case study).

Carer assessment will enable better systems and avoidance of assessment fatigue and repetition. It has become clear through this project that a carer will be faced by many different assessors and assessments. There is a need for services to appropriately share data and work together. This includes health, social care and any voluntary and community sector organisations who are involved in the provision of care, to ensure integrated care and best possible service and outcomes.

Current protocols and systems make it difficult or impossible for cross-service boundary sharing of information, which means telling the same story many times to many different people. A system of one trusted assessor supporting the carer through the assessment process and data sharing protocols would reduce such duplication for the whole family.

Appropriateness of service in timing, location and format is important. Just as the major focus has been on where the patient wishes to be treated and ultimately to die, there should be another focus on when, where and how the carer wishes to receive support and meeting these needs in a manner which also fits with their life outside caring.

Respect for carers as individuals, not as an add-on to a patient, is vital. So, too, is understanding that the carer’s need for information and support may well be different from (and sometimes even at odds with) the patient’s. Carers’ needs should be met by professionals and carer specialists; this will help ensure more successful, sustainable care packages.

The existence of a carer specialist service makes the assessment process and data sharing protocols. There is a need for services to appropriately share data and work together. This includes health, social care and any voluntary and community sector organisations who are involved in the provision of care, to ensure integrated care and best possible service and outcomes.

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Post-bereavement needs change but remain after the patient has died. The practical and emotional aspects of moving on may require continued support – funeral plans, changes to financial and legal documents and benefits, and an experienced listener. Joint support from specialist bereavement services may also be required and can be better introduced or provided by the trusted support worker.

Feedback on the experience from the carers’ perspective, to give the professionals involved, can be gained by the support worker without it feeling like an intrusion. This should result in a more honest, constructive and comprehensive feedback system.

Partnership working as a result of this pilot has embedded support in clinical settings to help secondary care recognise the role and value of the voluntary and community sector in specialist fields. This an important platform for us, and the wider NHS, to build on.