

Developing respite care at an inner London hospice

If patients' preferred place of care is their home, then it is crucial to help carers cope with their roles – which is what respite care should do. **Diane Lavery, Sara Faithfull and Anne Arber** look at the approach to respite care adopted by St Joseph's Hospice in London

In the UK, palliative care plays an important role in supporting patients and their carers during the course of a progressive and life-threatening illness. There has been much research into people's preferred place of care and death, the future care needs of an aging society and the lack of resources and services in the community to support people's wishes.^{1,2} There have also been numerous national drivers to emphasise and promote community-based care. Government documents and policies³ recognise the role of flexible respite care to maintain and sustain carers in their unsung roles, especially as they save the healthcare system a significant amount of money,^{4,5} particularly towards the end of life.⁶ The *End of Life Care Strategy*³ emphasised care in and by the community and avoidance of hospital admissions whenever possible, primarily to stick to patient preferences but also to reduce the cost of inpatient hospital care. The 2005 *National Service Framework for Long-term Conditions* stated that 'carers have a right to obtain the support and services they require for the person they care for and for themselves

as carers'.⁷ However, respite care, which provides support to patients (and their carers) and helps ensure they can remain in their own home, is a scarce resource.

What is respite care?

The most frequently adopted definition of respite care is that proposed by Miller as 'the temporary physical, emotional or social care of a dependent person in order to provide relief from care giving to the primary provider'.⁸ This is supported by research.^{9–11} The beneficiary of respite care is usually considered to be the informal carer (although there may also be benefits for the care recipient),^{12–15} as respite care decreases their burden, promotes their well-being^{16–18} and provides them with ongoing support.^{16,19,20}

Respite services may not necessarily be a 'discrete intervention'¹³ (one defined area of care) but a range of services in a variety of settings – day care in a centre on a weekly basis; intermittent care in the person's home, which may be a few hours at weekly intervals; or residential care in an institution, which may be from a few days to two weeks.^{4,9,13,17,21} It is vital that the correct service is identified to provide the appropriate support.^{22,23}

Key points

- Respite care is poorly developed despite the emphasis on allowing patients to be cared for in their preferred place – often their home.
- It is essential to support informal carers in continuing in their roles by providing adequate and timely relief from their duties.
- Patients who live alone with no informal carers should also be given the opportunity to have a change from their context of care.
- Respite care programmes should involve specific referral criteria, multidisciplinary triaging, predetermined admission and discharge dates, a thorough review of the patient and their caring context, and a structured programme of care and signposting.

Respite care at St Joseph's Hospice

St Joseph's Hospice in East London has developed a strategic plan aimed at strengthening the existing service provision by offering a full range of services to meet the varying needs and expectations of all patients, their carers and families, and to provide extra support for carers. The hospice wanted to put in place a facility that would allow each patient to maintain or regain as much independence as possible, with a comprehensive multidisciplinary team focused on rehabilitation working with the

patient, their carer and family. This was an ambitious aim that would require careful thought relating to the appropriate use of the hospice's beds. The emphasis of care would remain firmly entrenched in promoting a patient's self-care and control over their life, including the patient's and carers'/family's ability to cope with a life-threatening illness. It was also acknowledged that carers need to have time out from their caring role so that they can maintain good health and continue to care for the patient on an ongoing basis.

To understand respite care at the hospice, and in view of the increasing amount of literature, research and government documents supporting care at home, it was timely to review the inpatient respite care by conducting a retrospective case review (Phase 1). The purpose of the case review was to examine and agree appropriate bed usage and the feasibility of setting up a nurse-led respite service for the local boroughs served by the hospice. The goals were to determine what type of patients were being referred for 'respite', the actual reason for admission (determined at initial assessment), the length of stay, their needs during their stay and the outcome of the admission. This was followed by a pilot study (Phase 2), which involved establishing two additional beds in the existing inpatient wards to begin the development of a new respite service.

Setting

St Joseph's Hospice is situated in a large deprived urban area with people coming from diverse ethnic, cultural, religious, social and economic backgrounds. At the time, the hospice had a 32-bed inpatient unit. There are three community palliative care teams based at the hospice which work across three boroughs, and the hospice provides inpatient care for a further six boroughs. There is also a day hospice and an evolving outpatient service. In addition, the local communities are invited to utilise a non-clinical area offering information, advice and support to manage the impact and consequences of progressive and life-threatening conditions.

Historically, at St Joseph's Hospice, no beds were specifically allocated to respite care. Beds would be made available if they were vacant and if there were no patients waiting to be admitted for symptom control or terminal care, who were considered the priority.



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Phase 1 – Case review

The details of all patients referred for 'respite care' between April 2009 and March 2010 were obtained from the PalCare data system and the clinical notes were accessed. A proforma was developed to capture the data required for the case review. There were 55 patients referred for respite care during the study period, but 12 sets of notes were missing, resulting in 43 patients being reviewed. The age range was 46–97 years (mean 73 years). There was very little difference in gender (23 male, 20 female). The majority of patients were White British (22 patients, 51%) and lived across six of the nine boroughs. Thirty-four patients (79%) had been diagnosed with malignant disease and nine (21%) with non-malignant disease.

The main source of referral was acute hospital doctors (11 referrals, 25%), with GPs and specialist hospital or community teams also referring. Out of the 43 patients reviewed, 27 (63%) were admitted and 16 (37%) were not, due to a variety of reasons (no bed available, patient still undergoing active treatment with curative intent, family declining a hospice admission and patient not deemed to be appropriate for admission).

Out of the 27 admitted patients, 18 (67%) lived with a carer (13 with a spouse, three with a daughter and two with a son) and nine (33%) lived alone with no informal carers. Eleven patients with informal carers had no paid carers and four informal carers had their own health concerns.

The length of stay ranged from one to 85 days (mean 19 days). Most patients (14, 51%)

■ Respite care can help keep informal carers well and able to continue in their role, but can also give patients living alone a break from the context of their usual place of care

were known to the hospice. On admission, 17 (63%) patients were identified as having physical problems and two as being in the terminal stage. A recent deterioration had been documented in 11 (40%) of the patients.

Some patients had a predetermined date of discharge (13, 48%); out of these 13 patients, three (23%) died at the hospice and 10 (77%) were discharged. Conversely, there were 14 (52%) patients who had no predetermined date of discharge; eight of them (57%) died, only three (21.5%) were discharged and the remaining three (21.5%) were transferred to an alternative care setting as they were not well enough to return home (see Table 1).

When there was a social reason documented for admission, those reasons were: carer not coping (eight, 29%), carer in hospital (four, 14%) and carer on holiday (three, 11%). The actual documented reasons for admission (determined after assessment on admission) were: respite in 12 (44.5%) cases, symptom control in 10 (37.5%) and terminal care in five (18%) (see Table 2).

Phase 2 – Pilot study

In view of these findings and the recent appointment of a nurse consultant, a pilot study was conducted over ten months to trial a nurse-led service for patients requiring inpatient respite care. An additional bed on the existing two wards in the hospice was created and utilised for this purpose. Specific respite care referral criteria were devised (see Box 1). Referrals were triaged by a multidisciplinary team and, if they were considered appropriate, dates of admission and discharge were determined. The patient, carer and referrer were informed of these dates. The patient received an information leaflet detailing, for example, the importance of their continued routine, what to bring with them (medication, walking aids) and the aim of maximising their independence and functionality during their planned stay.

A multidisciplinary steering group was established to begin developing plans for this new service, in conjunction with the ongoing development of an operational policy.

According to an analysis of data from the first seven months of the pilot study, 24 patients were admitted for 29 episodes of care (five patients had more than one planned respite care admission). The majority of patients (22) stayed for a period of two weeks.

Table 1. Predetermined date of discharge

	Predetermined date of discharge? Yes	Predetermined date of discharge? No
	13 (48%)	14 (52%)
Died	3 (23%)	8 (57%)
Discharged home	10 (77%)	3 (21.5%)
Transferred	0	3 (21.5%)

The mean age of the 13 female patients was 65 years (range 44–76 years) and the mean age of the 11 male patients was 73 years (range 46–82 years). The majority of patients were White British, which is indicative of the general occupancy of the hospice (but not of the local population). The referrers were mainly the community teams (the respite service had not been widely advertised externally at this point). Forty-two per cent of patients lived alone and came for a break from the context of their care; 51% of admissions were to give carers respite; the remaining patients were admitted because of complex situations requiring a review of the care at home. Fifty-eight per cent of admitted patients had a non-malignant diagnosis (mainly respiratory and neurological).

During their planned stay, most patients required a low level of symptom control and rehabilitative or functional interventions. Only two had to be transferred to a medical colleague due to a deterioration of their condition and the need for higher-level medical intervention (such as intravenous antibiotics for sepsis). Most patients benefited from a wide multidisciplinary input. No patients died.

The respite programme involved a comprehensive multidisciplinary admission process (by a nurse consultant, staff grade doctor, ward nurse and therapist), a review of disease status and symptoms, the setting of goals that patients would like to achieve during their stay (review of functional status, introduction to the day hospice programme, and so forth) and the planning of activities and therapies (complementary interventions, review by a dietitian in case of poor appetite, weight loss or taste changes, and so forth). The day hospice and volunteers played an active role in the programme.

Discussion

Although specific referral criteria were not initially available, guidelines for referral and a general description of respite care were

available on the hospice's website (the referral criteria on the website were broad in scope, mentioning 'a structured approach to care' and recommended planned admission and discharge dates). Pressure on acute beds and a desire to get patients out of hospital and to a place of safety may have been foremost in healthcare professionals' minds when referring patients to the hospice for respite care, which may have resulted in patients being admitted with minimal thought for the type of admission required.

In Phase 1, most referrers were external, despite the busy community teams based at the hospice. Most patients had a cancer diagnosis rather than a non-cancer diagnosis – the former traditionally attracting more funding and resources. The hospice's strategic plan aimed to widen access to patients with non-cancer diagnoses; therefore, a stronger focus on these conditions was required.

Respite care is often linked with a 'crisis intervention' when the caring role breaks down at home.^{18,24} Lack of planning leads to a 'fire-fighting situation' where emergency support becomes necessary,^{10,25} which may not be viewed as a 'respite care' intervention.

In Phase 2, the pilot project provided an opportunity for patients to benefit from the input of a large multidisciplinary team and enabled patients to remain at home for long periods of time^{19,26,27} by providing their carers with time off and thereby supporting them to continue in their caring role.^{21,28,29}

Respite is described as both a 'service' (depending on the setting) and an 'outcome' (relief from care-giving),^{12,24} where additional therapies and interventions (such as physiotherapy and occupational therapy) can also be accessed.^{18,27} Patients who receive respite care are generally not considered to be medically complex; more emphasis is put on rehabilitation and functionality. Flexibility (of timing, frequency and activities) is considered crucial.¹⁶ At the time of referral, patients were thought to be medically stable and without overwhelming symptom control problems; therefore, their stay was suitable for rehabilitation and a general overview.^{25,30}

The fact that a date of discharge could be predetermined possibly shows that patients had been appropriately referred. No patients died during respite care and this may be indicative of referral criteria providing clarity and a triage system ensuring patients are

Table 2. Actual reason for admission (determined at initial assessment)

Respite	12 (44.5%)
Symptom control	10 (37.5%)
Terminal care	5 (18%)

Box 1. Dedicated respite referral criteria

People eligible for this service are:

- Patients who are medically stable
- Patients with a progressive and life-threatening condition living at home
- Patients for whom the unpaid carers need a break from caring
- Patients living at home alone who wish to have a break from care in this context

Priority will be given to:

- Patients who are thought to be in the last year of life. This can be determined by the patient being on the Gold Standards Framework register and asking other professionals caring for the patient their opinion of prognosis
- Patients who are at risk of increasing levels of dependency due to functional deterioration that may be retrievable

Any other mitigating factors, such as burden of illness, family and social factors, should be taken into consideration

appropriate for this type of admission. There was a significantly higher proportion of patients with non-malignant disease in Phase 2. This widening of access is encouraging; patients with long-term progressive diseases that do not have such a well-defined disease trajectory as cancer frequently need ongoing support and breaks.

There were a significant number of patients who had no informal carers. The literature suggests that respite care may be beneficial with regard to keeping carers well and able to continue in their role, especially as this involves cost-savings for the health service,⁴ particularly towards the end of life,⁶ but there has been minimal attention paid to, or studies looking at, respite services for patients living alone, despite this being acknowledged as an area of increasing need.^{10,31}

Kristjanson *et al* conducted a national descriptive survey of patients and carers of people with neurodegenerative conditions using numerous assessment tools to identify and compare the needs for supportive and palliative care services.³² One finding was the significant proportion of patients with

multiple sclerosis who were living alone with no carers at all. The benefits of receiving respite care when living alone are to give patients a break from the context of their usual place of care, providing a holistic assessment to review their care needs and signposting them to ongoing alternative support, such as befriending services and day services. More work is required in this area.

There were several challenges in Phase 2. The fact that the respite bed was in an 'acute' ward meant that the nursing staff needed to adopt a change of mindset when caring for respite patients. This was poorly achieved and, on reflection, mixing two philosophies of care was thought to be a cause of concern. Although this was a nurse-led service, as the respite patients were on an 'acute' ward, the default position was to contact the ward doctor to address any issues that could and should have been managed by nurses. Finally, respite patients found it difficult at times to focus on rehabilitation and maximising functionality, especially if they were in areas where other patients may be dying.

Respite care can be a poor relation to care related to more complex needs, such as symptom control; however, numerous documents, including the *End of Life Care Strategy*, refer to the importance of keeping patients in their preferred place of care, which frequently is their home. This may be more readily achieved if patients and their carers (when applicable) receive adequate support and timely intervention to ensure that they are able to stay at home for as long as possible.

Future plans

A dedicated nurse-led respite unit with eight beds has now opened at St Joseph's Hospice, which is widening access to all types of conditions that are life-threatening and progressive. Feedback from carers and patients has been very positive. Formal evaluation using a validated outcome measure (St Christopher's Index of Patient Priorities), qualitative interviews and focus groups are ongoing and involve patients, informal carers, referrers and staff.

In addition, further research is under way to look at patients with neurodegenerative diseases (as these patients and their carers would benefit from, and require more access to, respite care) and the role that a dedicated respite care programme may play for them.

Declaration of interest

The authors declare that there is no conflict of interest.

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