End of life care in care homes: Understanding and mapping innovative solutions

Executive summary

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Grant holders

Jane Seymour, Sue Ryder Care Professor of Palliative and End of Life Studies, School of Nursing, Midwifery and Physiotherapy, University of Nottingham

Dr Katherine Froggatt, Senior Lecturer, International Observatory on End of Life Care, Lancaster University

Researcher

Arun Kumar, Research Associate, School of Nursing, Midwifery and Physiotherapy, University of Nottingham

Correspondence to:

Professor Jane Seymour

Sue Ryder Care Centre for Palliative and End of Life Studies

School of Nursing, Midwifery and Physiotherapy

University of
Nottingham
Queen's Medical
Centre
Nottingham,
NG7 2UH
Telephone: 0115 8231202
Email: jane.seymour@nottingham.ac.uk

BACKGROUND

Care homes for older adults are an increasingly important site of palliative and end of life care delivery; in England approximately 17% of people over the age of 65 die in care homes[1]. Other residents with complex palliative care needs live in care homes before being moved to other care settings prior to their death. The delivery of good quality end of life care in care homes requires an effective balance of external support, such as systems to access medication and syringe drivers, with internal resources, such as staff who are well trained and who work in a supportive culture in which they are able to make residents' and their relatives' needs and concerns their first priority.

This document reports a study commissioned by the National End of Life Care Programme to examine these issues in relation to the care of older people in nursing homes[2]. The study was conducted by staff from the Sue Ryder Care Centre for Palliative and End of Life Studies at the University of Nottingham and from the International Observatory on End of Life Care at Lancaster University between September 2007 and November 2008.

The issues highlighted as a result of this report demonstrate that nursing homes are part of a larger system and the quality of their interrelationships with the various parts of that system determines the quality of end of life care they can provide. If a nursing home cannot access support externally, they have to work in isolation to provide end of life care and are the often the sole advocate for the residents in their care. Further, if a nursing home is unaware of specific support available in the wider system, absence of support may not be recognized and acknowledged, and their isolation and lack of confidence is compounded.

This study offers an insight into the experiences of nursing staff and key players in the wider health and social care system who work together, sometimes against the odds, to care for older people in their last days, weeks and months of life. Understanding what the issues are in coordinating such care and maximising the support provided to nursing home staff is vital to ensure that nursing home residents, who are among the most vulnerable adults in our society, receive the highest standards of care possible at the end of their lives. We hope this report will offer a starting point to stimulate further debate about the future of the wider care home sector and its role in end of life care.

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[1] Department of Health (2008) End of Life Care Strategy: Promoting high quality care for all adults at the end of life. London: Department of Health, p 9
[2] 'Care home' is a generic term for organisations offering either nursing care (nursing homes) and /or personal care (residential homes) for adults, of all ages. In this report we focus on care homes with nursing, using the term 'nursing homes'.

AIMS

The following project aims were developed through consultation with an expert steering group[3]:

- To identify the key drivers and barriers within the wider health and social care system influencing quality of end of life care in care homes with nursing for older people.
- To identify the key drivers and barriers influencing quality of end of life care intrinsic to care homes with nursing for older people.
- To develop practical guidance for the implementation of transferable solutions relating to the intrinsic and extrinsic factors which influence quality of end of life care in care homes with nursing for older people.

METHODS

A mixed methods design was employed, consisting of two in depth case studies of care homes and a complementary survey of 180 nursing homes surrounding the case study sites (90 surrounding each site). Mixed methods, which involve the application of different data collection strategies, are suitable for examining complex inter related research questions, for which one type of evidence will be inadequate. Such a design is particularly suitable for applied policy related research.

Ethics and governance approval

The fieldwork was conducted from April 2008 to September 2008. NHS ethics committee approval was gained in April 2008 and research and governance approval from the PCTS within which the case studies were located in was gained in May 2008 for case study 1 and July 2008 for case study 2.

Limitations

Since the study was small scale and exploratory, a decision was made to focus on nursing homes, as opposed to looking more generally at homes providing personal care (previously know as 'residential care homes). It is likely however, that some of the issues reported here are also relevant to the latter. Furthermore, the homes we studied as 'cases' were not part of a wider chain provider: this needs to be noted in making sense of the findings. There are a number of other limitations in the study. We were not able, for resource reasons, to access the views of older residents or their family carers about their experiences of care; nor, with one exception, were we able to gather the views of front line care assistant staff within care homes. Moreover, our purposive sampling of the two care homes with nursing that are the key case studies in the project meant that

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[3] A project steering group was appointed, which consisted the following individuals: The Palliative care lead for the Healthcare Commission (HCC) and The Commission for Social Care Inspection (CSCI); The National Programme Director and Manager for the End of Life Care Programme, The Director of Policy at English Community Council Association (ECCA), The coordinator of the 'My Home Life' Programme, The Nursing Director for the Registered Nursing Homes Association, The Executive Director for the National Care Forum, The End of Life Project Manager for the Mid Trent Cancer Network, The End of Life Coordinator for Public Health, Nottinghamshire County PCT.

it was clearly in their interests to present the care that they provided in a largely positive light. However, by conducting a survey of other care homes in the localities of the cares home involved in the case studies, we have been able to contextualise the case study findings and thus enhance the validity of the study's conclusions about the support which care homes need to provide appropriate end of life care. Furthermore, in their interviews with us staff were open and candid about the issues they faced in their daily work: they reported problems and ongoing challenges, as well as those things that were going well, communicating a sense of shared purpose in seeking to improve the capacity of care homes and build on the potential of care homes to provide excellent end of life care.

SUMMARY OF FINDINGS

Case studies

Two nursing homes providing support to older people were purposively selected as the case studies for the investigation. One was located in a large city and the other in a predominantly rural area. Both were privately owned. Both care homes were in Northern England and were chosen following consultation with colleagues from: the National End of Life Care Programme, care home associations and other local stakeholders in end of life care practice and policy. In each case study site, two approaches to data collection were employed: documentary analysis and interviews. Interviews[4] were with senior care home staff (n=7) and stakeholders (n=10) nominated by care home staff as people who provided help and support in end of life care.

Nursing home one, located in the city, was providing care to 58 residents at the time of the study. It had an integral unit for the delivery of intermediate and continuing care. Between January 1st and December 31st 2007, there were 30 residents who died in the home and 5 residents who died at the local hospital[c] . Nursing home two, in the rural area, was providing care to 44 residents at the time of the study. Between January 1st and December 31st 2007, there were 25 deaths among residents, of whom 23 died in the home and two died in the local hospital [h]. Table one summarises key findings from the case studies.

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[4] For details, see the main report

Table 1. Key findings from the case studies of nursing homes one and two

Nursing Home 1	Nursing Home 2
Structural conditions allowing development of end of life care practice	*Structural conditions allowing development of end of life care practice*
Tendered for and won a contract for the provision of continuing and intermediate care in 2003	Implement the Liverpool Care Pathway in 2006, following an attempt by the care home manager to seek out a method of 'smoothing' standards of end of life care
The first nursing home in the PCT to implement the Liverpool Care Pathway, in 2004	A community matron comes into post in 2006 with a remit to support care homes
Joined the National Gold Standards Framework (GSF) Programme for Care Homes in 2005	A community mental health care nurse comes into post in 2007 and supports the community matron in the care home work
Intrinsic factors	*Intrinsic factors*
A distinct philosophy of palliative and end of life care, strengthened by co staffing across the care home and continuing/ intermediate care unit and use of the pathways	An emerging philosophy of end of life care and clear aspirations for developing practice in end of life care. LCP seen as enabling this
Senior staff, who were in receipt of a palliative care certificate from the local hospice, showed leadership to others within and outwith the home	Leadership shown by senior staff in implementing the LCP and addressing problems in accessing extrinsic support
Learning and resource room in the home for use by all staff	Problems experienced in accessing training and education, especially where provided by the NHS. Staff paying and attending in own time
Shared emphasis on developing networks of communication with staff, key stakeholders, residents and relatives	Culture of good communication and regular staff meetings
Perceived support from care home owners, which has allowed relatively high staff-resident ratio	Perceived support from care home owners, which has allowed relatively high staff-resident ratio
Workforce perceived to be moderately stable and morale high	Workforce perceived to be moderately stable and morale high
Little reliance on district nurses	Some reliance on district nurses, who were a scarce resource in the locality with no clear remit to attend nursing homes
Extrinsic factors	*Extrinsic factors*
Staff invited to attend multidisciplinary meetings in the PCT relating to the GSF and palliative and supportive strategy more broadly	Care home staff not attending MDT meetings and felt relatively isolated from wider end of life care practice in the PCT
Links with and support from with GPs and Macmillan nursing services has improved as end of life care practice in house has developed. This has begun to resolve some medical staffing, prescribing and 'out of hours' problems	GP support has been problematic in the past and is still variable. Out of hours support perceived as not adequate
Well supported by key PCT staff and an informed commissioner	Well supported by key staff, especially community matron and community mental health nurse. Macmillan nursing only accessed for cancer patients. Perceived threat of non continuity of key roles in the PCT.
Selected to host a syringe driver library for use by other care homes. Funded by a Big Lottery Grant, gained by the LCP facilitator	Ongoing struggles to gain syringe driver access. Partially solved by purchase of one driver by the PCT for use by local homes.
Networking with other care homes is well developed	Networking with other care homes is under development.
No comments made about hospital information	Perceived lack of information about residents discharged from hospital

Survey
Care homes with nursing providing support to older people and surrounding each case study were surveyed using a postal questionnaire developed for the purpose from a review of previous questionnaires used in related research. It included a range of questions about the profile of deaths, support accessed, barriers experienced and perceived priorities for end of life care. The questionnaire was piloted at an end of life workshop for care homes in the locality of the care home at the centre of one of the case studies. Names and addresses of care homes with nursing care and registered to care for Old Age (not falling into any other category) were identified from the CSCI website. A 10-mile radius was selected appropriate for care homes surrounding the case study care home 1, which was located in a city (n = 90). A 20-mile radius was used as the inclusion criteria for care homes surrounding the case study care home 2, located in a rural area (n = 90). (The total response rate for the survey was 46% (82:180 surveys completed), with a

❖ 34% response rate (n=31) for nursing homes surrounding nursing home 1.
❖ 57% response rate (n=51) for nursing homes surrounding nursing home 2.

Of those homes that responded: 57% provided information about care home size (19-180 beds) and residents' deaths in the last year (76% residents died in the care home; 77% from non cancer conditions). Nursing homes were asked to describe their perception of the quality of end of life care provided. There was a 78% (n=64) response rate to this question, with 2% (n=1) describing the care they provided as "Needs improving", 4.7% (n=3) as "Average", 52% (n=33) as "Good", and 42% (n=27) as "Excellent".

Care homes which described the quality of end of life care they provide as "Needs improving" and as "Average" were not implementing any end of life care pathways. Seventy-nine percent (n=26) of care homes which described their end of life care as "Good" and 77% (n=20) of those which described their end of life care as "Excellent" were implementing an end of life care pathway, usually the Liverpool Care Pathway for the Dying.

72% of homes reported that they had a "a lot" of support from GP's, specialist palliative care nurses and district nurses and "some" support from family members and social workers; 56% said that support received varied with resident's illness and stage. Qualitative comments provide insight into barriers to care: variable and inconsistent GP support; discriminatory attitudes; lack of information about services/ resources/ training; poor 'out of hours' cover. Respondents had clear views about their priorities for enhancing end of life care, including: meeting residents and families needs; improving the care home environment; staff training and education; using end of life pathways; networking.

KEY THEMES FOR DISCUSSION

Using data from both parts of the study has enabled us to diagrammatically map the key facilitators and barriers to end of life care in nursing homes (see Appendix 1). A number of themes for discussion emerge.

The importance of leadership
Both the nursing homes studied as cases had very different contexts and conditions in which they were trying to develop their practice and for both, end of life care was only one aspect of their work. However both were remarkably similar in terms of the ability demonstrated by senior staff to show leadership and to engender aspirations for continual improvement of standards of end of life care, to maintain staff morale and to create a working environment in which staff turnover was reported to be relatively low. Both homes were actively engaged in networking with other homes in their locality, albeit at different stages of development, and both were fully aware of the range of problematic issues in relation to extrinsic support: one home had largely resolved many of the problems, while for the second home, this was very much 'work in progress'.

Inequalities in capacity to implement end of life care tools: a catalyst for compounding isolation
The survey showed that nursing homes which implement an end of life care tool, such as the GSF or LCP, were more likely to describe their end of life care as "Excellent" and "Good". From our case study data, specifically interviews with stakeholders, we can see that it is only those homes that are judged to have a sufficiently developed organisation, clinical leadership and reasonably stable workforce (often supported by a high CSCI rating), which are encouraged to implement such tools. These homes, as exemplified by nursing homes 1 and 2, have the capacity to address the resultant end of life care issues thrown up by the implementation process and to develop good practice which is then supported by key individuals such as GSF and LCP facilitators, and in turn influences wider practice and policy in the host PCT. Nursing home 1 particularly demonstrates the powerful synergy which can occur between factors such as: small scale practice innovation, personal aspirations, the provision of effective external links for networking and support, and wider changes in commissioning practice and attitudes. These all coalesced in nursing home 1, such that they had begun to overcome some intractable problems reported elsewhere. They are now in a position to provide support to other care homes in the locality and to be a 'beacon' of good practice. But questions need to be asked about those nursing homes which do not have such a fortunate set of circumstances: it was clear in both case study localities that some homes are excluded from the outside support which flows from participation in the LCP and GSF implementation process, where the latter become 'enablers' of practice development within the care home and levers of support outside it. Care must be taken to ensure that such isolation does not become a catalyst for the widening of inequalities rather than a factor which motivates key stakeholders in end of life care to concentrate their efforts in

such environments. Arguably, we have shown that a 'law of inverse care'[5] operates in the care home sector with regard to the support provided to them by colleagues in the wider environment.

Variability in access to outside resources: key staff
We have shown that the majority of nursing homes in both localities of our study have some access to specialist palliative care services, such as the Macmillan nursing service and/or local hospice in the form of a 24-hour advice. However, on a day-to-day basis, most support is provided to nursing homes by GPs and District Nurses, with some support reported to be provided by other agencies such as social services. There is some evidence, from the survey data, of a lack of knowledge in nursing homes about available resources and key staff who may be able to assist with end of life care, particularly for residents with needs arising from conditions other than cancer, such as dementia. It seems that external end of life care support provided to nursing homes, in most cases, is still predicated on a model of palliative care provision required for the classic 'cancer' trajectory, which is increasingly at odds with the reality of residents' needs. In the locality of case study two, it was clear that a major contribution to the ability of care home 2 to cope with the latter needs was the recently instigated help they received from a community matron and a colleague with whom she worked closely, a community psychiatric nurse, both of whom had special responsibility for care homes in that area. This is supported by the survey data from the locality of case study 2, where the support of a community matron was cited by many nursing homes as being accessed regularly. In contrast, in the locality of case study 1, the role of community matrons received little mention, reflecting the different interpretation of roles and allocation of responsibilities for community matrons between the two case study areas.

The role of district nurses and GPs in supporting and assisting nursing homes has emerged from this report as critical, yet subject to variation according to the particular culture and practices of the latter.

As far as district nurses are concerned, there has never been an expectation that they would have a role in nursing homes, thus their workloads do not lend themselves easily to covering demands made from this sector. District nurses may be concerned about the significant potential addition to their workload and thus worried about how to keep in check apparently 'inappropriate' requests they receive from care home nurses. However, it cannot be safely assumed that residents in nursing homes are in receipt of appropriate nursing care for their complex needs at the end of life. An incident reported in one of the case studies, in which a district nurse eventually, reluctantly, visited the home to lend support with setting up a syringe driver probably exemplifies a much wider phenomenon. In the locality of case study 1, this issue was being dealt with at the level of commissioning, as reported by the lead commissioner for continuing care, but it was clear that there was a long way to go before the issue was resolved in that

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[5] Hart JT (1971) The inverse care law. *Lancet,* Feb 27; 1(7696):405-12

particular PCT. In the locality of nursing home two, a less favourable commissioning culture appeared to be in evidence and as a consequence the problems relating to district nurse support were sharply apparent.

The case study and survey data highlight a similar variability in relationships between GPs and care homes, and the complex challenges faced by on both sides in establishing effective working relationships. It is clear that GPs wish to work effectively with nursing homes but are sometimes distrustful of the knowledge and competence of care home staff and worried, probably with good cause, about repeated calls on their time and expertise. On the other hand, nursing home staff are sometimes excluded from multi disciplinary team meetings at GPs surgeries which might otherwise be opportunities for them to develop networks of additional support and receive ongoing education in end of life care. In the examples of both the case study sites, good working relationships, which had been developed over a number of years, evidently existed between the case study homes and their GPs, with both adapting to new ways of working such that they could find approaches to meeting the needs of residents consistently and effectively. Nursing home 1 was also sending representatives to the MDT meetings hosted by local GPs surgeries and found that through these, they had developed a supportive wider network that seemed to reduce their reliance on GPs. Nursing home 2 remained excluded from these, although our interview data suggested that there was a possibility that this would be liable to change in the future. There are lessons to be learnt from the case study data about effective ways of working with GPS and different approaches that care homes and GP surgeries may wish to employ in providing a consistent and responsive medical service to residents who are reaching the end of their lives. What comes through most clearly however, is the role of the Liverpool Care Pathway and the Gold Standards Framework in providing nursing home staff with a framework for advocating for their residents' needs with GPs and other community based staff.

Variability in access to outside resources: information, funding, equipment, resources and training
It was clear both from the survey of nursing homes in case study localities 1 and 2, and from the case study data (particularly from case study 2) that there are some common and intractable problems that homes face relating to access to: reliable information about their residents who are discharged from hospital (a case of a resident discharged with clostridium difficile unbeknown to the staff in nursing home 2 is a stark example); 'out of hours' support and equipment, with syringe drivers being the most commonly cited problem. Moreover, in relation to access to resources for education and training, many homes not only did not know how to access training but staff also had to attend training in their own time and pay for this from their own pockets. Access to NHS training was perceived to be particularly difficult. This aggravated problems of lack of confidence and of isolation for many, and may contribute to the transient workforce in some. In our two case study examples, many of these shortcomings were made up by the considerable efforts of the staff, who tended to work well over their contracted

hours, and via the support of the home owners and one or two charismatic figures from the outside.

Facilitators to end of life care

The nursing homes that made up the case studies and those nursing homes that responded to the survey all had very clear views about what were their key priorities for improving end of life care. This sense of vision seemed to be a key factor in the ability of homes 1 and 2 to overcome and solve some of the problems they faced and to have a clear 'map' for future travel towards meeting their goals. The sense that nursing home staff are very much focused on the needs and best interests of their residents is perhaps the greatest facilitating factor in end of life care emerging from this project. They had been clearly inspired by the lessons they had learnt from the Liverpool Care Pathway and, for care home 1, the Gold Standards Framework: but these provided a framework of understanding rather than a new direction of care. Of course there were many other subsidiary factors beyond the use of pathways and clear goals and aspirations: both the case study homes, and homes which responded to the survey, pointed to the support they received from particular key staff. Both case study sites had the support of the home owners in maintaining an above minimum workforce. Both case study sites had managed to create a reasonably stable workforce and a good atmosphere within which staff worked and could raise concerns and have them addressed. Both had good relationships with residents and their relatives, and had built up an excellent reputation over a number of years, which contributed to trust and high morale among all parties.

Commissioning practices

One observation, which was made by a key stakeholder in this study, is that it is crucially important that PCTs take an active role in building capacity in order that the successful implementation of new initiatives reaches into nursing homes currently regarded as 'weak' or in some way failing. This will involve a commitment to providing stable funding streams for posts such as End of Life Care Facilitators and Education Trainers, currently usually appointed on fixed term basis. Such innovation will require a more engaged and informed mode of commissioning practice than has historically been the case in the care home sector: as another stakeholder observed, the usual mode of practice is to *'commission the service and then walk away'*, with the assumption made that care home fees and assessments for nursing care can cover all the needs that residents are likely to have. Nursing homes for older people must be seen as integral and critical to the wider mission of improving end of life care in local communities, which is increasingly marked by a complex mixed economy of care. It is largely older people who die and increasing numbers over the course of the 21st century will do so in long-term care. Commissioners must enable nursing homes to access the outside resources that they need to provide equitable care to their residents.

CONCLUSION

The problematic issues highlighted as a result of this report have often been described in terms of either the absence of clear and agreed standards, or as inadequacies in knowledge and training. However the acquittal of such inadequacies by suggesting that training of care home staff will solve these issues may simply add to them[6]. Rather, attention should in addition focus on challenging and those discriminative attitudes, beliefs and practices in the wider system that contribute to the isolation of nursing homes and enhancing the ability of homes to demonstrate leadership in practice development. Although this exploratory study has helped begin unravel the complex web of the wider system surrounding nursing homes, much more work is needed to enable integration of nursing homes into the wider systems of end of life care and to enable collaboration across organizational, institutional and funding boundaries.

RECOMMENDATIONS

For care home providers and staff

1. **Care home providers and staff from care homes may wish to create local networks for practice development by liaison with other local homes and to celebrate their potential for providing excellent end of life care.**

2. **Care home providers, staff, PCTS and local authorities should be aware that NHS Continuing Healthcare funded care, can be delivered in a care home setting (nursing and or personal care). It is available for end of life care, and can be fast tracked if necessary[7].**

3. **Care home providers and staff should be aware of the End of Life Strategy and the responsibilities of their local authorities and PCTs in providing ongoing support to them for residents' end of life care.**

4. **Care home providers and staff may wish to note that the implementation of end of life care tools can enable practice development and lever external support necessary to assist care homes in end of life care.**

5. **Care home providers and senior staff may wish to explore policies and strategies to develop leadership should be considered, including the designation of some homes in their network as 'beacons' of good practice.**

For SHAs, PCTs and local authorities

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[6] Macdonald AJD (2001) Maintaining older people's dignity and autonomy in healthcare settings: Whole system must be looked at to prevent degrading treatment. *British Medical Journal* 323:340.

[7] DH and National End of Life Care Progamme (2008) *Joint Statement re: NHS Continuing Healthcare Funding for End of Life Care within Care Homes (both nursing and personal care).* Available at: http://www.endoflifecareforadults.nhs.uk/eolc/files/DH-EoLC_Continuing_care_funding_Aug2008.pdf accessed 9th December, 08

6. **SHAs, PCT and local authorities may wish to examine issues of nursing, medical and equipment support to nursing homes and modify commissioning attitudes and practices accordingly, particularly with regard to out of hours practice and the availability and maintenance of syringe drivers.**

7. **SHAs, PCTs and local authorities, as they seek to respond to the End of Life Strategy, may wish to discuss how to enable and sustain involvement of nursing home representatives in end of life care strategy development.**

8. **SHAs and PCTs need to examine how care homes in their area receive GP support and to develop a strategic approach to ensuring that care home residents who are approaching the end of life receive consistent and coordinated medical care within their place of residence from a doctor who is familiar with them and their needs.**

9. **SHAs and PCTs need to pay attention to the contrast between those homes implementing such tools and those who are not yet able to do so. All homes need to be able to access outside support for their practice in end of life care so that it reaches the markers of quality under development.**

10. **SHAs and PCTs need to be cognisant of the high numbers of deaths among care home residents from non cancer conditions and in the presence of mental health needs, especially dementia[8]. The role of the community matron, where it includes a remit for care homes, may be one promising means of addressing this issue.**

11. **Provision and access to training for care home staff needs to be urgently examined by PCTs, to ensure that staff have the capacity to reach the quality markers for end of life care which are under consultation.**

For Acute Hospital Trusts

12. **Acute hospital Trusts will wish to examine their policies and practices regarding the provision of information to care homes about residents discharged from hospitals.**

13. **Acute hospital Trusts may wish to monitor admissions from care homes of residents in the last days of life, audit the reasons for admission and communicate these to SHA end of life care working groups and their local PCTs.**

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[8] This should be considered with reference to the forthcoming National Dementia Strategy, see:
http://www.dh.gov.uk/en/socialcare/deliveringadultsocialcare/olderpeople/nationaldementiastrategy/index.htm
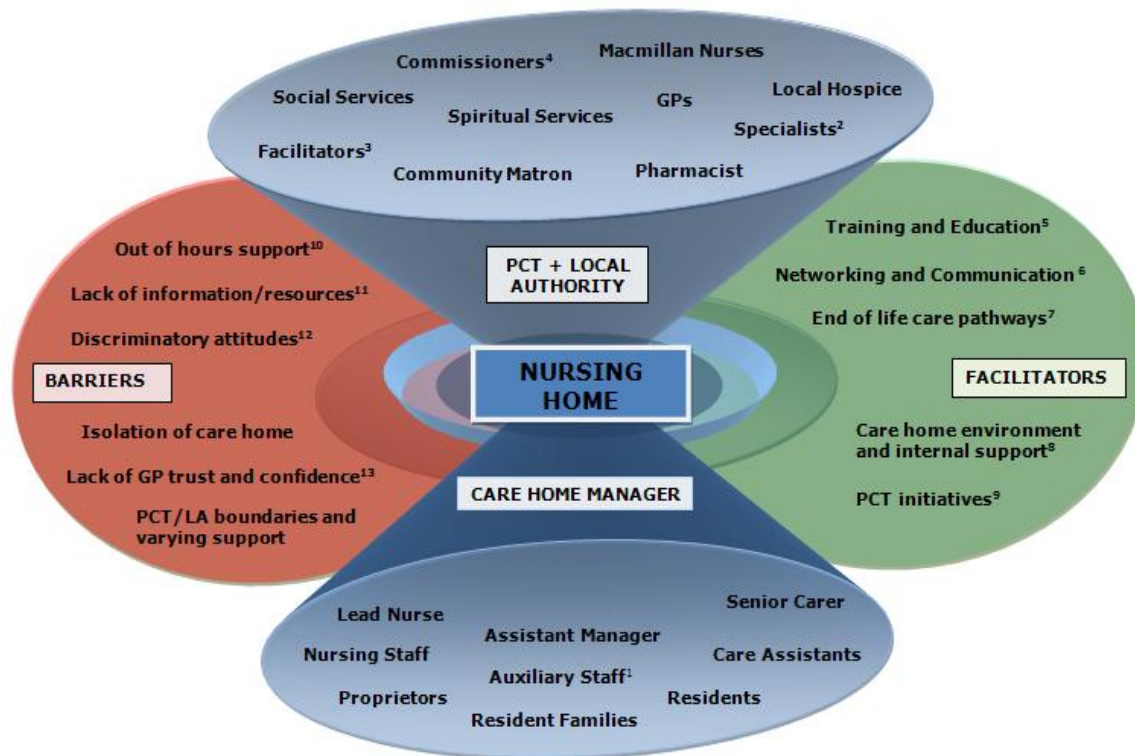accessed 9th December 08

NEXT STEPS

This report has informed the discussions of an 'Care Home Forum' convened by the National End of Life Care Programme, with representation from the project team and from a range of stakeholders, including the National Council for Palliative Care, Macmillan Cancer Support, Help the Aged, the Registered Nursing Homes Association, the English Community Care Association. A programme of work will be undertaken by the Forum to promote the needs and roles of care homes and their residents in relation to end of life care, with particular reference to highlighting issues of policy and practice to key stakeholders and agencies; mapping existing resources to support end of life care practice in care homes and where necessary contributing to the development of new resources which can be accessed at low or zero cost by care homes; identifying priority areas for research and practice development relevant to the development of end of life care in care homes.

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Sincere thanks go to the care home manager and staff at each case study site for giving their valuable time to take part in this study of end of life care in care homes. Thanks also to the PCTs in which each case study was located and their associated staff for their contributions. Care homes in each case study locality took the time to respond to a postal survey, for which we are very grateful. We were guided by an expert steering group and extend our thanks to: Andrew Makin - the Nursing Director for the Registered Nursing Homes Association, Ann Mackay - the Director of Policy at English Community Care Association (ECCA), Des Kelly - the Executive Director for the National Care Forum, Mary Casey and Virginia Storey at the Healthcare Commission (HCC) and The Commission for Social Care Inspection (CSCI); Gillian Whitworth – formerly End of Life Project Manager for the Mid Trent Cancer Network, Helen Scott – formerly End of Life Coordinator for Public Health, Nottinghamshire County PCT, Sheila Joseph - National Manager for the End of Life Care Programme and Tom Owen - the coordinator of the 'My Home Life' Programme. A special thanks also to Claire Henry, the National Programme Director for the End of Life Care Programme, who commissioned this study, for her support.

During the course of this study, Mary Casey, whose work in many ways inspired this project, died after a short illness. We would like to dedicate this report to Mary, in memory of her passionate concern about, and leadership in this field.

Appendix I: Mapping the barriers and facilitators to end of life care in care homes

¹ Auxiliary staff include:	**⁶Networking and Communication**	**⁹PCT Indicatives**
▪ Auxiliary Staff: e.g. administrative staff, catering, cleaning, laundry, maintenance, hairdressers, hobbies and activity coordinators.	▪ Link between commissioners and clinicians to promote end of life care pathways.	▪ Supportive and palliative care local strategy group
²Specialists including:	▪ Sharing good practice and transferable solutions within the care home and to other care homes	▪ Care homes project to support elderly people in care homes and prevent unnecessary hospital readmission.
▪ Specialist Palliative Teams, Community Psychiatric Nurse, Occupational Therapist, Physiotherapist, Geriatrician, Speech and Language Therapist, Dietetic Service, Counsellor, Chiropodist, Reflexologist, Acupuncturist.	▪ LCP and GSF steering groups ▪ Macmillan nurses advocating for care homes ▪ Develops GP trust and confidence ▪ MDT meetings, regular contact with GPs	▪ Syringe driver library and regular syringe driver training at local hospice
		¹⁰ Out of hours support
		▪ Difficulties to access prescribed pathway medication ▪ Inappropriate hospital admission ▪ Accessing syringe drivers
³Facilitators to include:	**⁷End of life care pathways, include**	**¹¹ Lack of information/resources**
▪ End of life care pathway facilitator ▪ LCP facilitator ▪ Education facilitator	▪ Liverpool Care pathway, Gold Standards Framework, Advanced Care Plans, and other local initiatives.	▪ Knowledge of training courses and support available
⁴Commissioners		**¹² Discriminatory attitudes**
▪ Service commissioner ▪ Continuing care	▪ Facilitates end of life discussions with staff, residents and their relatives.	▪ Apathy and prejudice towards end of life pathways and care homes ▪ Belief care home no longer entitled to services commissioned
⁵Training and Education	▪ Promotes confidence and pre-empts end of life care	▪ District nurses reluctance to support nursing staff
▪ Palliative and end of life care training e.g. Local hospice palliative care certificate	**⁸ Care home environment**	▪ Macmillan nurses apprehension in widening remit to support non-cancer residents
▪ Targeted and adapted to staff needs e	▪ Well maintained and organised ▪ Good communication between staff	**¹³Lack of GP support**
▪ Macmillan Healthcare assistant programme ▪ Use of end of life pathways ▪ GP education on end of life care pathways ▪ Refresher courses and cascading training	▪ Job satisfaction ▪ Keeping staff valued and passionate about care ▪ Low staff turnover ▪ Confidence in end life care ▪ Proprietor support	▪ Reluctance to prescribe LCP medication due to varying GP support, time constraints, monetary issues and lack of trust and confidence towards care home staff.