The Regulation and Quality Improvement Authority

# Reducing Hospital Admissions of People with Dementia from Nursing Homes: Anticipating Care Needs

## Phase 2

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Assurance, Challenge and Improvement in Health and Social Care

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## 1.0 BACKGROUND

Dementia is increasingly being recognised as a major public health issue and it is thought that 36 million people globally have a dementia diagnosis, which is expected to double in the next 15 years and triple by 2050.[1] Across Northern Ireland, the prevalence of dementia is increasing and it is predicted that this could triple from the current estimate of 19,000 to around 60,000 by 2051.[2] The impact on the lives of people with dementia, and those who matter to them, means that a response is required in relation to health and social care provision, to ensure that care and support for people with dementia is effective.

At a European level, palliative care is recognised as being relevant and important to people with dementia.[3] Across the world, concerns have been highlighted in relation to the unmet end of life care needs which people with dementia have[4] and the specific challenges and unmet information needs which their family/carers can experience[5].

The Worldwide Hospice Palliative Care Alliance[6] recognises the importance of palliative care in the management of dementia, which may continue for many years. However, acute episodes of illness can also occur, resulting in hospital admissions. In the United Kingdom, almost half of people over 70 years of age, with an unplanned hospital admission have dementia, and admissions from Nursing Homes are is common.[7] Research shows that people with a dementia diagnosis tend to have longer stays in hospital than those with a non-dementia diagnosis admitted for the same procedure.[7, 8] Therefore, people with dementia are at risk of adverse health outcomes due to hospitalisation, where they are in an unfamiliar environment, which can cause anxiety and confusion, and the longer hospital stays place extra financial pressure on the National Health Service.[9]

As acute episodes can happen at end of life, anticipating what people's needs are likely to be, is beneficial. .[10] There is evidence[11,12,13,14] that methods of anticipating care needs which can be successful in reducing hospital admissions ensure:

- that 'as needed' medication is available and prescribed in the care setting for use when required.

- that GPs have transferred all relevant information to the out of hours services.
- management and monitoring of common symptoms with appropriately trained staff.
- timely advance care planning in conjunction with the person and family, regarding their preferences and requests, in the event of their family members health deteriorating, including where they wish to be cared for at end of life.

An operational definition of advance care planning is; "a voluntary process of discussion with residents, and their families or carers, to make clear their wishes and thoughts for future care". Advance Care Planning is useful in the context of the person's deterioration where he or she may be unable to make decisions or communicate their wishes to other people. These aspects of anticipating care needs are linked to recognised care standards for Nursing Homes.[15, 16]

Reducing hospital admissions from Nursing Homes has been recognised as a priority area for action by a number of policy documents,[15,17,18] in addition to the emphasis placed on care in the community within the report 'Transforming Your Care'.[17] Relevant to this audit, 'Living Matters: Dying Matters',[18] the regional palliative and end of life care strategy in Northern Ireland, has included advance care planning and out of hours care as quality outcomes. The GAIN 'Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Homes'[15] contain best practice statements focused on anticipating the care needs of residents (advance care planning, anticipatory prescribing and care, out of hours care and staff training in palliative and end of life care). Phase 1 of this project assessed if these recognised strategies (within the best practice statements) to anticipate the care needs of residents and evidenced to reduce hospital admissions, were in place within nursing homes designated to people with dementia in Northern Ireland. These best practice statements were also the focus for this regional case note audit in Phase 2 during the period July 2017 to December 2017, across Nursing Homes designated to people with dementia in Northern Ireland. Phase 2 assessed whether recognised strategies, linked with anticipating the care needs of residents, to reduce hospital admissions have been implemented in practice within Nursing Homes designated to people with dementia.

# 2.0 AIMS & OBJECTIVES

## 2.1 Aim

The aim of the audit was to assess if recognised strategies, linked with anticipating the care needs of residents, in order to reduce hospital admissions, have been implemented in practice within Nursing Homes designated to people with dementia. Based on the findings, recommendations would be made, designed to reduce the number of hospital admissions for people with dementia in Nursing Homes.

## 2.2 Objectives

The objectives of Phase 2, aligned with the GAIN 'Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Homes'[15] were to:

- identify the number of residents with dementia who died having had their preferred place of care at end of life recorded.
- determine the number of residents with dementia who died in their recorded preferred place of care at end of life.
- ascertain the number of and reasons for hospital admissions that residents with dementia had during their stay in Nursing Homes.
- assess the level of implemented best practice in advance care planning for residents with dementia in Nursing Homes.
- ascertain if Nursing Homes had implemented best practice in relation to out of hours care and anticipatory prescribing and care.
- determine the level of involvement and impact of local specialist palliative care teams in end of life care of people with dementia in Nursing Homes.
- make recommendations for policy, practice, education and further service development.

# 3.0 METHODOLOGY

This is Phase 2 of a dual Phase Audit funded by RQIA during 2017/2018. Phase 1 was a regional audit of all Nursing Homes designated to people with dementia in Northern Ireland. The audit was designed to determine how strategies to anticipate the care needs of residents in order to reduce hospital admissions, had been implemented within Nursing Homes, during the retrospective audit period January 2015 - December 2015.

This report focuses on Phase 2, which consisted of a case note audit within Nursing Homes designated to people with Dementia in Northern Ireland (n=112). The case note audit was designed to determine whether strategies linked to anticipating care needs of residents had been implemented in practice, within Nursing Homes, designated to people with dementia in Northern Ireland.

## 3.1 Data Collection

The case note audit took place between July 2017 and December 2017. Nursing Homes designated to people with dementia (n=112) and Nursing Home managers were identified from the Regulation and Quality Improvement Authority (RQIA) database, which was accessed by a member of the RQIA audit team who sat on the project Steering Committee.

Nursing Homes were asked to complete an electronic proforma, (Appendix 1), with each home auditing case notes relating to three residents with dementia who had recently died. There was a consensus within the Project Team and Steering Group that this was the most pragmatic approach to take due to the archiving of case notes shortly after a resident had died. It was hoped that this would avoid the complication of trying to retrieve notes that had been archived and would 'simplify' the process for the nursing homes. Therefore, it was not possible to use the same time-frame as that used for Phase 1 (January 2015 - December 2015). The content of the audit proforma was informed by the project objectives, recognised best practice statements within the GAIN Guidelines (2013), (Appendix 2) and through consultation with the Regional Audit Project Team and Steering Group. The Regional

Audit Project Team and Steering Group included representatives from Nursing Homes participating in the audit and a service user representative. The members of this joint committee assisted in developing and piloting the audit proforma, to ensure clarity and appropriateness of questions and to make any necessary amendments.
To maximise responses from Nursing Homes, the Dillman[19] method was utilised. The original invitation and details about how to take part in the case note audit, were electronically circulated to the managers of all Nursing Homes designated to people with dementia in Northern Ireland (n=112). The audit proforma was sent electronically to homes on 11th July 2017 with a return date of 8th August 2017. As this generated a response from only six Nursing Homes, the audit proforma was then sent by post, with each Nursing Home receiving a paper copy to complete and return using an enclosed stamped addressed envelope. To facilitate an increased response rate, Nursing Homes were asked to self -audit the case notes of only one resident with dementia who had recently died. The audit proforma was forwarded to the managers of Nursing Homes designated to people with dementia on 13th October 2017 with a return date of 10th November 2017. During December 2017, the Project Lead offered a number of Nursing Homes who had not responded, the opportunity to complete the audit proforma by telephone.

### 3.2 Data Analysis

The audit proforma consisted of both qualitative and quantitative questions and data extracted were analysed to obtain descriptive statistics in the form of frequencies and percentages.

Data generated from open ended, qualitative questions were analysed into codes and categories.

### 3.3 Confidentiality & Data Protection

Nursing Home managers by completing and submitting the audit proforma implied consent for participation in the audit. Data Protection principles were adhered to by:

- anonymising all data.
- electronic data being stored on a password protected pc.

- paper copies of data being stored securely in a locked filing cabinet in a locked room in the School of Nursing & Midwifery, Queens University, Belfast.

## 4.0 FINDINGS

**Table 1: Summary of Breakdown of Finding from Phase 2 Audit**

| Objective | Percentage Achieved |
|---|---|
| Response rate | **40% (45 of 112)** |
| Identify the number of residents who died with preferred place of care at end of life recorded | **84% (38 of 45)** |
| Determine the number of residents who died having achieved recorded preferred place of care at end of life | **80% (36 of 45)** |
| Ascertain the number of and reasons for hospital admissions that residents with dementia had during their stay in Nursing Homes | **98% (44 of 45)** |
| Assess the level of implemented best practice in advance care planning with residents with dementia in Nursing Homes | **98% (44 of 45)** |
| Ascertain if Nursing Homes had implemented best practice in relation to;<br>• Out of hours<br>• Anticipatory Prescribing | <br><br>**80% (36 of 45)**<br>**80% (32 of 40)** |
| Determine the number of nursing homes that reported involvement from local specialist palliative care teams in end of life care of people with dementia | **20% (9 of 45)** |

Nursing Homes with dementia category identified from RQIA database (112). Forty-five Nursing Homes completed a proforma, (Appendix 1), with each Nursing Home auditing case notes relating to one resident with a recorded diagnosis of dementia who had recently died.

All Nursing Homes designated to people with dementia in Northern Ireland (n=112) were invited to take part in the regional case note audit. This generated a response rate of 40% (n= 45). Twenty-four of these Nursing Homes participated in both parts of this dual phase audit.

Nursing Home companies owned the majority of participating Nursing Homes 78%, (35 of 45) and the remainder 22% (10 of 45), were single Nursing Homes. The number of beds designated to people with dementia in responding Nursing Homes ranged from four to sixty-seven.

A descriptive outline of the 45 Nursing Homes, which participated in the audit, can be found in Appendix 3. The regional geographical spread of responding Nursing homes across the five Health and Social Care Trusts is available in Appendix 4.

### 4.1 Resident Information

Nursing Homes were asked to provide information, which focused on:

- the resident having a recorded diagnosis of dementia.
- the number of hospital admissions from the Nursing Home.
- the length of stay in the Nursing Home.
- reasons for hospital admissions.
- recorded preferred place of care at end of life.
- resident's actual place of death.

### 4.2 Diagnosis of Dementia Recorded on Resident's Case Notes

All of the 45 Nursing Homes that responded confirmed that the resident, whose case notes they audited, had a recorded diagnosis of dementia.

### 4.3 Number of Hospital Admissions, for Residents from their Nursing Home

Ninety-eight percent (44 of 45) of Nursing Homes provided information on the number of hospital admissions, which residents had, from their Nursing Home. Thirteen residents had no hospital admissions and their stay in the Nursing Homes ranged from one to 12 years. Three individual residents had six, eight and nine admissions respectively and their stay in the Nursing Homes ranged from two years and six months to four years. Table 2 shows collectively the number of hospital admissions for residents**.**

**Table 2: Hospital Admissions by Number of Residents**

| Number of Hospital Admissions | Percentage | Number of Residents (n=45) |
|---|---|---|
| 0 | 29% | 13 |
| 1 | 22% | 10 |
| 2 | 22% | 10 |
| 3 | 13% | 6 |
| 4 | 4% | 2 |
| 6 | 2% | 1 |
| 8 | 2% | 1 |
| 9 | 2% | 1 |
| Not known | 2% | 1 |

### 4.4 Resident's Length of Stay in the Nursing Home

The majority of residents 80% (36 of 45) had lived in their Nursing Home for 2-5 years whilst two residents had resided in their Nursing Home for 11-15 years (Table 3).

**Table 3: Resident's Length of Stay in the Nursing Home**

| Length of Stay | Percentage | Number of Residents (n=45) |
|---|---|---|
| 0-1 years | 13% | 6 |
| 2-5 years | 80% | 36 |
| 6-10 years | 2% | 1 |
| 11-15 years | 4% | 2 |

### 4.5 Reasons for Hospital Admissions

A number of reasons were cited by Nursing Homes in relation to residents' hospital admissions. Chest infection was the most common reason reported by 20 Nursing Homes, seven Nursing Homes reported falls as triggering hospital admission whilst others cited the need for intravenous fluids and antibiotics. These findings correspond with those of Phase 1, where participating Nursing Homes reported that the most common reasons for residents' hospital admissions were injuries due to a fall or chest infections.

### 4.6 Resident's Recorded Preferred Place of Care at End of Life

The audit sought to identify the number of residents with a recorded preferred place of care at end of life. This is thought to be important in reducing hospital admissions, particularly, if it has been determined that the resident wishes to remain in the Nursing Home at end of life.

Table 4 shows that the majority of residents 84%, (38 of 45) had Nursing Home recorded as their preferred place of care. Of these residents, 95% (36 of 38) died in their preferred place of care at end of life. Six residents had no preference recorded and one resident had not wished to discuss this issue.

**Table 4: Residents Recorded Preferred Place of Care at End of Life**

| Preferred Place of Care at End of Life | Percentage | Number of Residents (n=45) |
|---|---|---|
| Nursing Home | 84% | 38 |
| Hospice | 0 | 0 |
| Own home | 0 | 0 |
| Hospital | 0 | 0 |
| Did not wish to discuss | 2% | 1 |
| No preference recorded | 13% | 6 |

*Data from Table 4 were mapped to Table 5 in relation to actual place of death for each resident.*

### 4.7 Resident's Actual Place of Death

From the data reported in Table 5, 89% (40 of 45) of residents had died in their Nursing Home and 11% (5) of residents died in hospital.

Of the five residents who died in hospital, three had no preference recorded in their case notes, one resident did not wish to discuss their preferred place of care at end of life and one resident had a preferred place of care recorded as their Nursing Home.

**Table 5: Resident's Actual Place of Death**

| Place of Death | Percentage | Number of Residents (n=45) |
|---|---|---|
| Nursing Home | 89% | 40 |
| Hospital | 11% | 5 |
| Hospice | 0 | 0 |
| Own home | 0 | 0 |

### 4.8 Palliative Care Register

The use of a Palliative Care Register was an initiative promoted within Nursing Homes through the implementation of the 'Guidelines for palliative and end of life care in Nursing and residential Homes' (GAIN 2013). In identifying residents with palliative care needs, it was envisaged that this would prompt the staff in Nursing Homes to consider the need for an advance care planning discussion, if this had not already taken place.

#### 4.8.1 Recording of Residents' Name on the Palliative Care Register

In Phase 1 of the dual audit, only 23% (9 of 39) Nursing Homes reported they had a palliative care register in place which included residents with dementia.

In Phase 2, 47% (21of 45) Nursing Homes reported that the resident's name was recorded on their palliative care register. Seventeen (38%) Nursing Homes reported that they did not have a palliative care register within the Nursing Home. The remaining seven (16%) Nursing Homes reported that the resident's name was not recorded within their palliative care register (Table 6). Of the seven Nursing Homes who reported that the resident's name was not recorded within their palliative care

register; three residents had not taken part in advance care planning nor had the best interest discussion with residents' family carers been recorded as having taken place.

**Table 6: Recording of Residents' Name on the Palliative Care Register**

| Residents Name Recorded on Palliative Care Register | Percentage | Number of Residents (n=45) |
|---|---|---|
| Name recorded on the Palliative care register | 47% | 21 |
| Name **not** recorded on the palliative register | 16% | 7 |
| Nursing Home **did not have** a palliative care register | 38% | 17 |

### 4.9 Identification of the Palliative Care Key Worker within Residents' Case Notes

The palliative care key worker was identified within the resident's case notes in 38% (17 of 45) Nursing Homes, whilst 62% (28 of 45) of Nursing Homes reported that the key worker had not been identified (Table 7).

**Table 7: Palliative Care Key Worker Identified in Residents Case Notes**

| key worker identified | Percentage | Number of Residents (n=45) |
|---|---|---|
| Key worker identified in residents' case notes | 38% | 17 |
| Key worker not identified in residents case notes | 62% | 28 |

### 4.10 Advance Care Planning Discussion

Advance Care Planning is a voluntary process of discussion with residents and their family/carers to make clear their wishes and thoughts for future care. Advance care planning is useful if a resident's condition deteriorates to a point where he/she may be unable to make decisions or communicate their wishes to other people.

### 4.10.1 Record of an Advance Care Planning Discussion Having Taken Place Prior to the Resident Losing Capacity

Twenty-nine (64%) of Nursing Homes reported that an advance care planning discussion had not taken place prior to resident losing capacity and 33% (15 of 45) Nursing Homes indicated that it had taken place prior to resident losing capacity. One Nursing Home reported that they did not know if this record was available (Table 8).

The small number of residents who had taken part in advance care planning mirrors the comments of Nursing Home managers in Phase 1, who reported that most residents with dementia had lost capacity to take part in advance care planning prior to admission to the Nursing Home.

**Table 8: Advance Care Planning Discussion Prior to Resident Losing Capacity**

| ACP discussion prior to losing capacity | Percentage | Number of Residents (n=45) |
|---|---|---|
| Yes | 33% | 15 |
| No | 64% | 29 |
| Don't know | 2% | 1 |

Table 9 shows outcomes arising from the advance care planning discussions for the 15 Nursing Homes where discussions had taken place prior to the resident losing capacity. Nursing Homes could provide more than one response and 25 records were involved across five outcomes.

**Table 9: Outcomes from Advance Care Planning Discussion**

| Outcomes from Advance Care Planning discussion | Number of Residents |
|---|---|
| Statement of Resident's Wishes | 7 |
| Preferred Place of Care at End of Life Identified | 8 |
| Advance Decision to Refuse Treatment | 4 |
| Power of Attorney | 5 |
| Other: Resident's wishes discussed with family | 1 |

This question generated more than one response from Nursing Homes

### 4.10.2 Timeframe for Advance Care Planning Discussion (prior to resident losing capacity)

Fifteen Nursing Homes indicated that advanced care planning had taken place prior to the resident losing capacity (Table 8). Of these, three reported that the advance care planning discussion had taken place prior to admission to the Nursing Home; five reported the discussion had taken place within three months of admission and seven reported the discussion had taken place after three months of admission to Nursing Home (Table10).

**Table 10: Timeframe for Advance Care Planning Discussion (prior to resident losing capacity)**

| Timeframe for Advance Care Planning Discussion | Percentage | Number of Residents (n=15) |
|---|---|---|
| Prior to admission to Nursing Home | 20% | 3 |
| Within 3 months of admission to Nursing Home | 33% | 5 |
| After 3 months of admission to Nursing Home | 47% | 7 |

### 4.11 Recorded information concerning the resident's 'Do Not Attempt Resuscitation Status

Nursing Homes were asked to indicate if the 'Do Not Attempt Resuscitation Status' was recorded within residents' case notes. Ninety-six percent (43 of 45) case notes had this information recorded and 4% (2 of 45) did not (Table 11).

**Table 11: 'Do Not Attempt Resuscitation Status' Recorded on Resident's Case Notes.**

| Do Not Attempt Resuscitation Status | Percentage | Number of Residents (n=45) |
|---|---|---|
| Information recorded on residents case notes | 96% | 43 |
| Information **not** recorded on residents case notes | 4% | 2 |

### 4.12 Best Interest Discussion with Family Carers

Best interest discussions take place where it is not possible to include the person in decisions regarding their care (e.g. where they are no longer able to communicate their wishes). Decisions will be made in their best interests and their previously known wishes will be taken into consideration. Their family will be included in the decision process.

#### 4.12.1 Recording of best interest discussion

Within the majority of Nursing Homes 84% (38 of 45) a best interest discussion had been recorded in the resident's case notes; seven Nursing Homes (16%) indicated there was no record of a best interest discussion (Table 12).

**Table 12: Best Interest Discussion Recorded in Resident's Case Notes.**

| Best interest discussion with family/carers | Percentage | Number of Residents (n=45) |
|---|---|---|
| Information recorded on residents case notes | 84% | 38 |
| Information **not** recorded on residents case notes | 16% | 7 |

With reference to the five residents who died in hospital (Table 5), it was noted that a best interest discussion had taken place with four of these residents. The remaining one resident had not taken part in advance care planning nor had a best interest discussion taken place with family/carers.

#### 4.12.2 Timing of Best Interest Discussion

Thirty-eight Nursing Homes (84%) recorded in residents' case notes that best interest discussions had taken place with family/carers. Of these, 50% (19 of 38) Nursing Homes had participated in a best interest discussion within three months of the resident's admission and 50% (19 of 38) had participated in this discussion after three months of admission (Table 12).

**Table 13: Timing of Best Interest Discussion with Family Carers**

| Timeframe of Best Interest Discussion with Family/Carers | Percentage | Number of Residents (n=38) |
|---|---|---|
| **Within** 3 months of admission to Nursing Home | 50% | 19 |
| **After** 3 months of admission to Nursing Home | 50% | 19 |

## 4.13 Out of Hours Care, Anticipatory Prescribing and Care

### 4.13.1 Record of discussion about out of hours care

This section of the audit focused on the available records that evidenced a discussion about out of hours care for the resident. Data collected also provided information as to whether or not anticipatory prescribing had taken place. Table 13 shows that Nursing Homes reported there was a record of discussion about out of hours care for 80% (36 of 45) of residents. Seven Nursing Home managers, who completed the case note review by telephone, provided additional information and stated that an out of hours care discussion normally took place during the resident's annual review.

No other details were collected as to the content of this out of hours care discussion.

**Table 13: Record of discussion about out of hours care**

| Discussion about out of hours care | Percentage | Number of Residents (n=45) |
|---|---|---|
| Yes | 80% | 36 |
| No | 20% | 9 |

### 4.13.2 Unnecessary Medications Discontinued when the Resident's Imminent End of Life was Identified

Eighty seven percent (39 of 45) Nursing Homes reported that unnecessary medications had been discontinued for the resident and 13% (6 of 45) Nursing Homes reported they had not been discontinued.

### 4.13.3 Recording of Anticipatory Medication Prescribing at End of life

Anticipatory medication prescribing is key to enabling residents to stay in their place of care, as this pre-empts what they may require particularly during the out of hours period. In anticipating what might happen to the resident, medication that he or she may require can be anticipated and prescribed, and made available in the nursing home for administration.

Eighty-nine percent (40 of 45) of residents died in their Nursing Home and of these, 80% (32 of 40) had a record of anticipatory medication prescribing and 20% (8 of 40) did not have this recorded (Table 14).

**Table 14: Record of Anticipatory Medication Prescribing**

| Record of anticipatory medication prescribing | Percentage | Number of Residents (n=40) |
|---|---|---|
| Yes | 80% | 32 |
| No | 20% | 8 |

### 4.13.4 Availability of Anticipatory Medications

Of the 40 residents who died in their Nursing Home, Table 15 shows that anticipatory prescribed medication was available for 78% (31 of 40) residents. Nursing Homes anticipatory prescribed medication was not available in 15% (6 of 40) homes and 8% (3 of 40) Nursing Homes did not respond to this question.

**Table 15: Availability of Anticipatory Medications**

| Anticipatory medication available | Percentage | Number of Residents (n=40) |
|---|---|---|
| Prescribed anticipatory medication was available | 78% | 31 |
| Prescribed anticipatory medication was not available | 15% | 6 |
| Information not provided | 8% | 3 |

### 4.13.5 Availability of Necessary Equipment. (e.g.: a syringe driver to deliver medication at end of life)

Equipment was available when needed within 44% (20 of 45) Nursing Homes, for example a continuous sub-cutaneous infusion syringe driver. The remaining 56% (25 of 45) Nursing Homes reported that this equipment was not required.

## 4.14 Involvement of Local Specialist Palliative Care Team

Twenty percent (9 of 45) of Nursing Homes involved the local specialist palliative care team in the resident's care at end of life. The majority (80%, 36 of 45) of the Nursing Homes did not require this specialist involvement.

### 4.14.1 Reason for the Involvement of the Local Specialist Palliative Care Team

Two Nursing Homes (NH21 and NH37) indicated that involvement of the local specialist palliative care team had been primarily to access a syringe driver, to administer medication to the resident at end of life. The remaining seven Nursing Homes had done so for pain and symptom assessment and pain management as well as to support the family/carers and Nursing Home staff during the end of life care period.

### 4.14.2 Impact of the Local Specialist Palliative Care Team

Nursing Homes reported that the impact of the local specialist palliative care team had been positive and commented on the support and advice provided to Nursing Home Staff.

| **Comments from Nursing Homes in relation to Impact of local specialist palliative care team:** |
|---|
| *'Had a good impact, all MD (Multi-Disciplinary) Team worked together to provide the best standard of care…visited every week to see patient…offer support'. (NH Manager 21)* |
| '*Extremely attentive to resident's needs. Provided more support to staff and additional opinion/varied experience and viewpoint' (NH Manager 37)* |
| *'No change to care given, but staff appreciated support and knowledge offered' (NH Manager 19)* |

Nursing home staff perceived that the care and comfort through good pain and symptom management, provided by the palliative care specialists, had enabled homes to maintain the resident in the Nursing Home environment.

| **Comments from Nursing Homes in relation to impact of local specialist palliative care team on resident care:** |
| --- |
| '*To manage pain, nausea, seizure, respiratory secretions, agitation and distress and liaise with nursing staff regarding effectiveness of prescribed medication. This would prevent, where possible, hospital admission (NH Manager 21)* |
| '*Care given to resident to ensure pain free and comfortable. Also give staff the support they needed in dealing with patients at end of life' (NH Manager 3)* |

Nursing Homes also commented that palliative care specialists facilitated communication in relation to sensitive end of life conversations with family carers.

| **Comment in relation to local specialist palliative care team communication with residents family:** |
| --- |
| '*Open communication with family. Best interests of resident- doing what is best for resident. Their home/ care home is best' (NH Manager 30)* |

Other comments forwarded related to training. These comments focused on the need for training of Nursing Home staff and GPs to promote competence and confidence in palliative and end of life care, leading to a reduction in hospital admissions.

### 4.15 Nursing Home Comments in Relation to Anticipating Care Needs

**Nursing homes were asked to share their comments in relation to anticipating care needs to reduce hospital admissions from Nursing Homes for residents with dementia..**

Nursing Home managers highlighted the importance of working closely with GPs. They considered that if more resources were allocated to the Out of Hours GP Service this could enable more GPs to visit the residents, when required, during evenings and weekends, which would decrease the need for hospital admissions. As comments below indicate, this involved the role of the GP in Advance Care Planning,

in anticipating care needs and in working closely with the nursing home in the provision of pain management.

| **Comments in relation to anticipating care needs to reduce hospital admissions of residents with dementia from Nursing Homes:** |
|---|
| *'Ensuring ACP (Advance Care Planning) is undertaken as soon as possible and updated and reviewed regularly. To attempt at all times to care for the resident in their own environment to reduce symptoms of dementia'. (NH Manager 21)* |
| *'GP fully involved, anticipatory prescribing in place from immediate identification of end of life process'. (NH Manager 26)* |
| *'If GP is proactive and works with the home and pain relief is there' (NH Manager 44)* |

Nursing Homes also highlighted the need for team working and shared decision making with the family/carers of residents:

| **Comment from Nursing Homes on shared decision making:** |
|---|
| *Family were involved with best interest decisions about father's preferred place of care. GP had suggested hospital admission, but met with family-GP willing to honour relatives' preferred place of care' (NH Manager 12)* |

Staff recognised the need for more family/carer education to promote their preparedness as they accompanied their family member on their last journey of life. Time was required to have these sensitive conversations so that families were clear about what was happening and ensure that appropriate advance care planning for the resident could take place.

| **Comments from Nursing Homes on family carer education:** |
|---|
| *'If families are well informed and realistic about the outcome. Talk at length (with family) about end of life and the journey relative is to take' (NH Manager 44)* |
| *'Important to have discussion with family when you see deterioration so that when end of life comes it is clear what family wants to happen re: resident' (NH Manager 45)* |
| *Family education in relation to end of life - when families are aware of deterioration families decide to take relatives to hospital…quite often regret admission' (NH Manager 7)* |

There was a sense from comments made by Nursing Home staff that reducing hospital admissions was closely linked to staff preparedness and competence to care for residents at end of life. The perceptions of one Nursing Home manager were that the number of residents' hospital admissions at end of life had decreased due to recent staff palliative care training.

| **Comment relating to reducing hospital admission for residents:** |
| --- |
| *'Staff completed palliative care course in Trust recently. Hospital admissions down in the home due to training'. (NH Manager 5)* |

Nursing Home managers commented that nursing staff training should be provided to help to reduce hospital admissions and therefore enable residents to stay in their nursing home environment.

| **Comments relating to Nursing Home training for staff :** |
| --- |
| *'If our nurses can administer medication ie: IV fluids can help-more training for nurses…competence'. (NH Manager 11)* |
| *'Decision made over the 'phone…ambulance. Increase training of IVs for nurses. Residents to be treated in familiar environment'. (NH Manager 15)* |
| *'Training on IV fluids would help re: dehydration'. (NH Manager 16)* |

In the absence of nursing staff competencies in certain skills, having access to external expertise and equipment outside of the Nursing Home was valuable. The importance of partnership working, to facilitate access to resources from the 'primary care team' (i.e.: District Nurse and General Practitioner) and 'specialist palliative care team, was also recognised'. The important role of the 'Acute Care at Home Team' in managing and treating crises in nursing homes, such as when intravenous fluids and/or intravenous medication were required, was also highlighted.

| **Comments relating to partnership working:** |
| --- |
| *'At present the 'Acute Care at Home Team' will attend to residents in the re: IV Antibiotics/IV Fluids. Service is new and there has been a drop in hospital admissions'. (NH Manager 1)* |

| |
|---|
| *'Can contact the Trust and Specialist Palliative Care Team, District Nurses and can access resources (i.e. Syringe Driver) - Nursing Home and the Trust are working together and it works'. (NH Manager 5)* |
| *'Acute Care at Home Team' has provided excellent care to our residents in palliative care. They enable our residents to stay in their home'. (NH Manager 35)* |

# 5.0 DISCUSSION

Phase 2 of this audit had a 40% response rate (45 of 112), across private Nursing Homes in Northern Ireland designated to people with dementia.
A regional case note audit took place with regional geographical representation across the five HSCTs. The majority, 78% of responding Nursing Homes, were part of a Nursing Home company and the remainder 22% were single Nursing Homes.

## 5.1 Residents' Hospital Admissions

All of the 45 Nursing Homes that responded confirmed that the resident whose case notes they audited had a recorded diagnosis of dementia. Thirteen residents had no hospital admissions and had resided in the Nursing Home for one to 12 years. The most common reason for hospital admission was chest infection, which was cited by almost half of responding Nursing Homes.

## 5.2 Residents' Preferred Place of Care at End of Life

The majority 84% (38 of 45) of residents had their preferred place of care at end of life recorded as the Nursing Home. Forty residents (80%) died in the Nursing Home and of those, 36 of 40 had their final wishes met, in relation to their recorded preferred place of care at end of life. No other preferred place of care at end of life was noted within case notes for the remaining four residents.

## 5.3 Palliative Care Register

Evidence of good practice was demonstrated by 62% (28 of 45) of Nursing Homes by having a palliative care register. Of these nursing homes, 21 had the resident's names recorded on the register. These Nursing Homes have recognised that the resident had palliative care needs and had the right to quality palliative and end of life care[3]. Residents' inclusion on the palliative care register[15] can also prompt Nursing Home staff to consider 'advance care planning' with residents' family/carer and/or a 'best interest discussion' with the family/carer. Of the seven residents, whose names had not been recorded on the register, five had not taken part in

advance care planning, but a best interest discussion had occurred and two had taken part in both advance care planning and best interest decision making.

### 5.4 Advance Care Planning Prior to Resident Losing Capacity

The audit identified that 33% (15 out of 45) residents with dementia who had capacity, took part in advance care planning. This reflects the reported experience of Nursing Home managers who took part in Phase 1 of this dual audit and underlines the advanced stage of the disease at which this population is often admitted to Nursing Homes. This also highlights the importance of timely discussions with this population about their wishes and preferences, prior to nursing home admission, due to the gradual cognitive decline, which can occur[20]. The audit identified three Nursing Homes where advance care planning had taken place with the resident prior to their Nursing Home admission.

### 5.5 Best Interests Discussion

A best interest discussion with family/carers was recorded in the majority of residents' case notes 84% (38 of 45) suggesting examples of good practice in partnership working and shared decision making with family/carers. The timing of this discussion appeared to vary, with 50% (19 of 38) of these Nursing Homes reporting that they had taken part in a best interest discussion with family carers within three months of the resident's admission and the remaining 50% reporting participation in best interest discussion after three months of admission.

### 5.6 Out of Hours Care

Two related factors, the out of hours GP service and anticipatory prescribing are recognised as a key parts of anticipating care needs to reduce hospital admissions for people from their own Home or Nursing Homes[13]. These require close liaison between Nursing Home staff and the GP, to anticipate needs and plan ahead, enabling residents to remain in their place of care.

Nursing Home managers reported that in relation to 80% (36 of 45) of residents, an out of hours care discussion had occurred. Seven of these Nursing Home managers,

who completed the case note review by telephone, provided additional information and stated that an out of hours care discussion normally took place during the resident's annual review.

### 5.7 Anticipatory Prescribing

Unnecessary medications were discontinued for the majority, 87% (39 of 45) of residents. The rationale for this question was that it is standard practice that as the resident approaches the last stage of their life, medication, in relation to what is needed for the management of pain and other symptoms is normally prioritised. For those residents who died within their Nursing home (40 of 45), anticipatory medication prescribing was recorded for 80% (32 of 40) residents and was available in the Nursing Home for 78% (31of 40) residents.

Equipment (such as a syringe driver to deliver medication at end of life) appeared to be available for the residents who required it, as indicated by 44% (20 of 45) responding Nursing Homes. For the remainder 56% (25 of 40) of Nursing Homes there were no reports that equipment was required.

### 5.8 Impact of Involvement of Local Specialist Palliative Care Team

There is evidence that input from specialist palliative care teams can be beneficial to the care and comfort of people with dementia residing in Nursing Homes[21]. Nursing Homes had reported involvement of the local specialist palliative care team in the care of nine residents. For some Nursing Homes, this involvement was necessary to gain access to a syringe driver to deliver the required medication for residents. Other Nursing Homes required input to help with residents' pain and symptom management, and to provide support for both the family members and Nursing Home care team.

Information provided by Nursing Home managers about the impact that the specialist palliative care team had on resident's care, highlighted their specialist role and positive input. Their role involved working supportively in partnership with the care team in the Nursing Home and with the resident and their family carer. Nursing Home managers considered that the expertise provided by the local specialist

palliative care team in pain and symptom management helped to prevent hospital admissions.

Nursing Home managers reported that the Nursing Home care team benefited from the support and training made available to them through the local specialist palliative care team in relation to providing end of life care. One Nursing Home manager felt that there was a need for more palliative care training for the Nursing Home care team and they also considered that palliative care training for GPs would a be beneficial. However, challenges exist within Nursing Home settings in sustaining knowledge and skills in palliative and end of life care, due to the transient nature of the workforce.[22]

In Nursing Home settings, in addition to training provided by the specialist palliative care team, the Dementia Learning and Development Framework,[23] contains a self-assessment tool, outlining the key knowledge and skills, which are required for health and social care professionals to care effectively for a person with dementia and their family carers, including at end of life. Other core competency tools[24] have been developed for 'the multi-professional team' to identify current knowledge and skills in palliative and end of life care and areas for further development. Frameworks such as these may be helpful for care teams in Nursing Homes to assess and plan competency based training based on identified needs.[25]

## 5.9 Nursing Home Managers Comments in relation to Anticipating Care Needs.

Nursing Home managers had the opportunity to provide comment in relation to anticipating care needs of residents with dementia in order to reduce hospital admissions.

The comments highlighted the importance of good team working with GPs as pivotal and cited examples of good practice in joint working. These examples related to the timely introduction and updating of an advance care plan, evidence of engagement with the GP in relation to anticipatory prescribing and availability of medication for the resident at end of life. One Nursing Home provided an example of joint working and shared decision making with family/carers, which enabled a resident to remain in the Nursing Home as their preferred place of care.

Comments provided by Nursing Home managers recognised that there was a need for family/carer education in relation to end of life care. This would enable them to consider and make decisions, at different stages of the resident's end of life care as their relative started to deteriorate. This concept of empowering family/carers, through education, to take part in sensitive discussions about end of life care is supported by literature.[22, 26]

The impact of palliative and end of life care training, accessed through the local trust, was considered to have reduced hospital transfers in one Nursing Home.

Nursing Home managers frequently mentioned the need for skill(s) acquisition in use of intravenous fluids and antibiotics, as the lack of this knowledge appeared to have a strong connection to the need to transfer residents to hospital. In the absence of these clinical skills amongst the care team in Nursing Homes, the 'primary care team' and 'Acute Care at Home Team' were useful external resources, which could be accessed. In particular, the 'Acute Care at Home Team' could give intravenous antibiotics.

# 6.0 EVIDENCE OF GOOD PRACTICE

The findings from this regional audit, have demonstrated a number of examples of good practice and areas for service development.

## 6.1 Record keeping

- 84% (38 of 45) of Nursing Homes had the residents preferred place of care at end of life recorded.
- 84% (38 of 45) had recorded that the best interest discussion with family/ carers had occurred (when the resident was unable to communicate their wishes/preferences).
- 62% (28 of 45) of Nursing Homes had a palliative care register.
- 96% (43 of 45) had recorded the 'Do Not Attempt Resuscitation Status' within resident's case notes.
- 80% (36 of 45) of Nursing Homes reported that there was a record of discussion about out of hours care.

Findings have shown examples of good practice in team working between the care team and GPs in anticipating care needs, to help to reduce hospital admissions such as the use of anticipatory prescribing:

## 6.2 Medication for residents at end of life

- The majority of Nursing homes, 87% (39 of 45) had unnecessary medication discontinued at end of life
- 80% (32 of 40) of those residents who died in the Nursing Home setting had anticipatory medicine prescribing recorded in case notes
- 78% (31 of 40) of Nursing Homes reported that the prescribed medication was available for residents.

## 7.0 AREAS FOR DEVELOPMENT

- Timely advance care planning with residents is necessary prior to the Nursing Home admission and prior to cognitive decline. The audit reported that only a small number (15 of 45) of residents had taken part in advance care planning, as most residents with dementia had lost capacity prior to admission to the Nursing Home.
- More family/carer education is required to promote preparedness for best interest discussions at end of life.
- The need for specific clinical skills in palliative and end of life care, has been identified within the Nursing Home care team.
- Further investigation into the factors which lead to a decision to admit a patient with advanced dementia to hospital and how these can be addressed is necessary.
- Better utilisation of the palliative care register within Nursing Homes and the Identification of the palliative care key worker within the resident's case notes (audit reported 38% (17 of 45) of Nursing Homes had this recorded).

## 8.0 LEARNING FROM AUDIT

The audit encountered challenges when engaging with and obtaining audit data from Nursing Homes and these included:

- Nursing Homes' capacity to fully engage with Phase 1 and Phase 2 of this dual audit process was restricted due to staff resources and time available to access the data required to complete the audit proformas.
- The audit period from Phase 1 was changed for Phase 2, due to the archiving of case notes off site by a number of the larger Nursing Home companies. This led to a new audit period being selected for phase 2 (as the data would then be available to staff on site).
- Data collection was initially requested via an on-line electronic proforma. However, due to the low response rate a hard copy (postal) version of the Proforma was provided. A small number of telephone interviews (7) were also conducted, but due to project's limited resources this could not be offered to all Nursing Homes.

## 9.0 RECOMMENDATIONS

Based on the findings of this dual phase audit project the following recommendations are made for implementation by Nursing Homes:

- The Nursing Home Care team should receive training in palliative and end of life care appropriate to their area of responsibility. Training content as applicable should include:

    1) Holistic Assessment
    2) Advance Care Planning
    3) Communication Skills
    4) Diagnosing Dying
    5) Assessment and Management of Symptoms
    6) Care of the Syringe Driver
    7) Out of Hours Care
    8) Feeding and Hydration
    9) Dementia and Frailty

- Timely discussions relating to planning ahead for people with dementia should take place prior to Nursing Home admission.

- Family/carer education should be developed, to prepare them to understand the progression of frailty and dementia, and to participate meaningfully in best interest discussions. Family/carer education should also be evaluated.

- Consideration should be given to an application for further funding to use a qualitative approach to obtain more in depth, rich data and insights into palliative and end of life care within Nursing Home settings. This should include the perceptions of GPs in relation to anticipating care needs at end of life.

## Project Team

| Name | Designation | Organisation |
|---|---|---|
| Dr Dorry McLaughlin (Project Lead) | Lecturer in Palliative Care & Chronic Illness | School of Nursing & Midwifery, Queen's University, Belfast |
| Dr Gillian Carter | Lecturer in Chronic Illness | School of Nursing & Midwifery, Queen's University, Belfast |
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| Dr Aine Abbott | General Practitioner/ MacMillan GP Facilitator | Western Health and Social Care Trust |
| Linda Graham | Nursing Home Manager | Four Seasons Health Care |
| Rema Borland | Oncology and Palliative Care Facilitator for Nursing Homes | Belfast Heath and Social Care Trust |
| Lesley Nelson | Community Specialist Palliative Care Physiotherapist | South Eastern Health and Social Care Trust |

## Regional Advisory/Steering Team

| Name | Designation | Organisation |
|---|---|---|
| Lorraine Kirkpatrick | Regional Manager | Four Seasons Health Care |
| Chris Walsh | Business Support Manager | Larchwood Care Homes and Care Circle Homes |
| Oonagh Grant | Nursing Home Manager | Glencarron Private Nursing Home |
| Lesley Rutherford | Nurse Consultant in Palliative Care | Marie Curie Hospice, Belfast, Belfast Health & Social Care Trust and Queen's University, Belfast |
| Joanne Ballentine | Project Lead for Hospice Enabled Dementia Partnerships Project | Northern Ireland Hospice |
| Gordon Kennedy | Family Carer and Service User | Not Applicable |
| Siobhan Crilly | Regional Clinical Audit Facilitator | Regulation and Quality Improvement Authority |

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## APPENDIX 1: PHASE 2 AUDIT PROFORMA

### Reducing Hospital Admissions of People with Dementia from Nursing Homes

**Dear Nursing Manager**

**We are asking nursing homes designated to the care of people with a dementia diagnosis to identify one resident who has died within the last 12 months and complete this case note review proforma. The proforma will take approximately 15-20 minutes to complete.**

**Please remember the importance of data protection and ensure that the anonymity of residents and families are maintained at all times.**

**Please return completed proforma on or before the 10 November 2017 using the prepaid envelope provided.**

**An electronic link to the case note review proforma is also available and has been provide to nursing homes via an email from audit@rqia.org.uk - if this would be a more convenient method of completion and return of the proforma for you.**

**Thank you in advance for your contribution to this project.**

### Nursing home information

1. Nursing Home Information: Please tell us the;

Name of Nursing Home:

Address of Nursing Home:

Name of staff member - completing case note review:

Designation of staff member - completing case note review:

2. Please indicate from list below the HSC Trust Location you nursing home is situated within;

- ◯ BHSCT
- ◯ SEHSCT
- ◯ SHSCT
- ◯ NHSCT
- ◯ WHSCT

## Information about the resident

3. Did this resident have a diagnosis of dementia recorded on their case notes?

- ◯ Yes
- ◯ No - If no please select another resident with a diagnosis of dementia recorded on their case notes who has recently died?

4. Please tell us the number of hospital admissions which the resident had from your nursing home? If none please indicate with a 0

5. What was the resident's length of stay in the nursing home (if the resident spent time in hospital please include this in your calculation for the length of stay in the nursing home).

Years:

Months:

6. Please briefly outline the reasons for any hospital admissions for this resident

7. Please indicate the resident's recorded preferred place of care at end of life:

- ◯ Nursing home
- ◯ Hospital
- ◯ Hospice
- ◯ Resident did not wish to discuss preferred place of care at end of life
- ◯ Own home
- ◯ No preference recorded
- ◯ Other (please specify)

8. Please indicate the resident's actual place of death:

- ◯ Nursing Home
- ◯ Own home
- ◯ Not recorded
- ◯ Hospice
- ◯ Hospital
- ◯ Other (please specify)

## Palliative Care Register

**Palliative Care Register prompts GP and nursing home staff to consider the need for an advanced care planning discussion (if not already in place).**

9. Is the resident's name recorded on the Palliative Care Register?

- ◯ Yes
- ◯ No
- ◯ Nursing home do not have a Palliative Care Register

10. Is the Palliative Care key worker identified in the resident's case notes?

- ◯ Yes
- ◯ No

## Advance Care Planning Discussion

**Advance Care Planning is a voluntary process of discussion with residents and their families /carers to make clear their wishes and thoughts for future care. Advance care planning is useful in the context of the resident's deterioration where he/she may be unable to make decisions or communicate their wishes to other people.**

11. Is there a record of an advance care planning discussion having taken place **prior to the resident losing capacity**?

- ◯ Yes
- ◯ No

12. If 'Yes' to Q11 - Please indicate any outcomes which were recorded from this advance care planning discussion **prior to resident losing capacity** (tick all that apply).

- ☐ Statement of resident's wishes
- ☐ Advance Decision to Refuse Treatment
- ☐ Preferred place of care identified
- ☐ Power of Attorney

Other - please tell us other outcome(s) recorded

13. If 'Yes' to Q11 - Please indicate when this advance care planning discussion took place with the resident (tick one only).

- ◯ Before admission to the nursing home
- ◯ Within 3 months of admission
- ◯ After 3 months of admission

Other - please tell us

14. Is there recorded information concerning the resident's - Do Not Attempt Resuscitation Status?

- ◯ Yes
- ◯ No

## Best Interest Discussion with family/carer(s)

**Best interest discussions take place where it is not possible to include the person in decisions regarding their care (e.g. where they are unable/no longer able to communicate their wishes). Decisions will be made in their best interests and their previously known wishes will be taken into consideration. Their family will be included in the decision making process.**

15. When the resident was unable to communicate their wishes/ preferences is there a record of the best interest discussion having been undertaken with family/carer(s)?

- ◯ Yes - best interest discussion recorded
- ◯ No - best interest discussion not recorded

16. When did this best interest discussion occur?

- ◯ Within 3 months of admission
- ◯ After 3 months of admission
- ◯ No best interest discussion recorded as undertaken with family/carer(s)

## Out of Hours Care and Anticipatory Care Prescribing

**Nursing home staff will liaise with resident's GP to ensure that specific written information is available within nursing home.**

17. Is there any record of a discussion about Out Of Hours Care for the resident?

- ◯ Yes
- ◯ No

18. When the resident's imminent 'end of life' was identified - Were unnecessary medication(s) discontinued?

- ◯ Yes
- ◯ No
- ◯ Not applicable - (resident not cared for within nursing home at this stage)

19. Is there a record of anticipatory medication prescribing for the resident at end of life?
(e.g. subcutaneous medications necessary to manage common end of life symptoms on a PRN basis)

- ◯ Yes
- ◯ No
- ◯ Not applicable - (resident not cared for within nursing home at this stage)

20. Were these anticipatory medications prescribed, available when appropriate?

- ◯ Prescribed anticipatory medication was available
- ◯ Prescribed anticipatory medication was unavailable
- ◯ No anticipatory medication prescribed
- ◯ Not applicable - (resident not cared for within nursing home at this stage)

21. Was any needed equipment available i.e. a syringe driver to deliver medication at end of life?

- ◯ Yes ◯ No ◯ None required
- ◯ Not applicable - (resident was not cared for within nursing home at this stage)

**Involvement of Local Specialist Palliative Care Team**

22. Was the local specialist palliative care team/hospice involved in the resident's care at end of life?

- ◯ Yes
- ◯ No

23. If yes to Q22; please tell us the reason for the involvement of the local specialist palliative care team/hospice?

5

24. If yes to Q22; tell us briefly what impact (if any) this involvement of the local specialist palliative care team/hospice had on the resident's care?

25. Please share with us any other comments in relation to anticipating care needs to reduce hospital admissions of residents with dementia from nursing homes?

**Returning your information**

**Thank you for taking the time from your busy schedule to complete this case note review your contribution to this project is greatly appreciated.**

**A stamped addressed envelope has been provided to return your completed case note review on or before 10th November 2017.**
**If you would prefer to return your case note review via email please scan your completed case note review and forward to;**
**d.mclaughlin@qub.ac.uk**

## APPENDIX 2: BEST PRACTICE STATEMENTS MAPPED TO PROFORMA from GAIN GUIDELINES FOR PALLIATIVE AND END OF LIFE CARE IN NURSING HOMES (2013)

**STANDARDS** **MAPPED TO PHASE 2 PROFORMA**

If criteria refer to detail given in other standards (e.g. local protocols/guidelines), please attach a copy of these standards or provide a website reference

| | Criteria | Target (%) | Exceptions | Evidence | *Strength | Instructions for where to find data |
|---|---|---|---|---|---|---|
| 1 | • The home holds a palliative care register and has a system in place to ensure that this is updated regularly and communicated to staff in a timely manner<br>• Inclusion on the palliative care register prompts the GP, staff in the home and the key worker to consider the need for an advance care planning discussion, if this has not already taken place. | 100% | | *(Mapped to Q.9&10)*<br>p.16 Best Practice 1<br>p.16 Best Practice 9 | C | Guidelines and Audit Implementation Network (2013) Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Homes |
| 2 | • Every resident is given the opportunity to develop an advance care plan within three months of admission.<br>• This includes the opportunity to discuss their wishes including their preferred place of care at the end of life. | 100% | Resident has advanced dementia and is unable to participate in advance care planning | *(Mapped to Q.7, 11,12,13 &14 )*<br>p.16 Best Practice 9<br>p.25 Best Practice 4 | | Guidelines and Audit Implementation Network (2013) Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Homes |

| | Criteria | Target (%) | Exceptions | Evidence | *Strength | Instructions for where to find data |
|---|---|---|---|---|---|---|
| 3 | • Where it is not possible to include the person in decisions regarding their care (e.g. were they are unable to communicate), decisions will be made in their best interests and their previously known wishes will be taken into consideration.<br>• The family will be included in the decision making process. | 100% | Resident has no family members nor significant others | *(Mapped to Q.15,16 )*<br>p.17 Best Practice 3 | C | Guidelines and Audit Implementation Network (2013) Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Homes |
| 4 | • Where the person is considered to be definitely in the last months or weeks of life, staff in the homeHome will liaise with the GP to ensure there is written information available within the home regarding the person's Do Not Attempt Resuscitation Status.<br>• Out of Hours handover form is completed.<br>• Unnecessary medication is discontinued and alternative anticipatory medication prescribed and available when appropriate. | 100% | | *(Mapped to Q.14, 17, 18,19, 20, 21)*<br>p.17 Best Practice 10<br>p.34 Best Practice 4 | C | Guidelines and Audit Implementation Network (2013) Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Homes |

| | Criteria | Target (%) | Exceptions | Evidence | *Strength | Instructions for where to find data |
|---|---|---|---|---|---|---|
| 5 | • The GP completes a handover form to advise out of hours and ambulance services which includes decisions from the advance care plan and any advance decision to refuse treatment/do not attempt cardiopulmonary resuscitation status. | 100% | | *(Mapped to Q.17)* p.26 Best Practice 8 | C | Guidelines and Audit Implementation Network (2013) Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Homes |
| 6 | • Staff in the home, the GP and other members of the multidisciplinary and specialist palliative care teams work together as appropriate to plan care.<br>• The person (if appropriate) and/or their family are involved in the decision making processes. The plan of care includes:<br>– All unnecessary medications are discontinued.<br>– Anticipatory prescribing- subcutaneous medications necessary to manage common end of life symptoms are prescribed on a PRN basis.<br>– | 100% | | *(Mapped to Q.18, 19)* p.34 Best Practice 4 | C | Guidelines and Audit Implementation Network (2013) Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Homes |

| Criteria | | Target (%) | Exceptions | Evidence | *Strength | Instructions for where to find data |
|---|---|---|---|---|---|---|
| 7 | • Based on the Palliative and End of Life Competency Assessment Tool (HSC, 2012) palliative and end of life care education should include:<br>– Principles of holistic assessment<br>– Communication Skills<br>– Advance Care Planning<br>– Identifying and diagnosing the deteriorating and dying person<br>– Managing common symptoms at end of life<br>– Management of a syringe driver<br>• Staff know who on the team has the knowledge, skills and competence to sensitively and appropriately initiate an advance care plan discussion with residents and their families. | 100% | | *(Audited in Phase 1, but not specifically audited in Phase 2 Case Note Review )*<br>p.42 Section 7.2 Bullet points<br>p.25 Best practice 3 | C | Guidelines and Audit Implementation Network (2013) Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Homes |

**APPENDIX 3: DESCRIPTIVE OUTLINE OF NURSING HOMES (n= 45) WHO RESPONDED TO PHASE 2 AUDIT PRESENTED WITH HSC TRUST GEOGRAPHICAL AREA**

| Nursing Home ID | Geographical Region | Number of Beds Dedicated to Dementia | Company or Single Home |
|---|---|---|---|
| NH 2 | BHSCT | Dementia x 15 | Company Home |
| NH 3 | BHSCT | Dementia x 34 | Company Home |
| NH 9 | BHSCT | Dementia x 14 | Company Home |
| NH 10 | BHSCT | Dementia x 28 | Company Home |
| NH 14 | BHSCT | Dementia x 27 | Company Home |
| NH 16 | BHSCT | Dementia x 45 | Company Home |
| NH 17 | BHSCT | Dementia x15 | Company Home |
| NH 33 | BHSCT | Dementia x 36 | Company Home |
| NH 42 | BHSCT | Dementia x 41 | Company Home |
| NH 15 | NHSCT | Dementia x14 | Company Home |
| NH 19 | NHSCT | Dementia x 67 | Company Home |
| NH 24 | NHSCT | Dementia x 43 | Company Home |
| NH 25 | NHSCT | Dementia x 13 | Company Home |
| NH 28 | NHSCT | Dementia x 28 | Company Home |
| NH 30 | NHSCT | Dementia x 22 | Company Home |
| NH 43 | NHSCT | Dementia x 20 | Single Home |
| NH 45 | NHSCT | Dementia x 22 | Company Home |
| NH 5 | SEHSCT | Dementia x 52 | Company Home |
| NH 6 | SEHSCT | Dementia x 38 | Company Home |
| NH 7 | SEHSCT | Dementia x 21 | Company Home |
| NH 8 | SEHSCT | Dementia x 12 | Company Home |
| NH 11 | SEHSCT | Dementia x 36 | Company Home |
| NH 12 | SEHSCT | Dementia x 41 | Company Home |
| NH 20 | SEHSCT | Dementia x 11 | Company Home |
| NH 22 | SEHSCT | Dementia x 21 | Company Home |
| NH 27 | SEHSCT | Dementia x 35 | Single Home |
| NH 29 | SEHSCT | Dementia x 40 | Company Home |
| NH 39 | SEHSCT | Dementia x 28 | Company Home |
| NH 4 | SHSCT | Dementia x 20 | Company Home |
| NH 13 | SHSCT | Dementia x 14 | Company Home |
| NH 31 | SHSCT | Dementia x 8 | Single Home |
| NH 34 | SHSCT | Dementia x 33 | Company Home |
| NH 35 | SHSCT | Dementia x 19 | Single Home |
| NH 38 | SHSCT | Dementia x 4 | Single Home |
| NH 40 | SHSCT | Dementia x 37 | Company Home |
| NH 41 | SHSCT | Dementia x 5 | Single Home |
| NH 44 | SHSCT | Dementia x 24 | Company Home |
| NH 1 | WHSCT | Dementia x 16 | Company Home |
| NH 18 | WHCST | Dementia x 20 | Company Home |
| NH 21 | WHSCT | Dementia x 7 | Single Home |
| NH 23 | WHSCT | Dementia x 38 | Company Home |
| NH 26 | WHSCT | Dementia x 42 | Single Home |
| NH 32 | WHSCT | Dementia x 14 | Company Home |
| NH 36 | WHSCT | Dementia x 25 | Single Home |
| NH 37 | WHSCT | Dementia x 26 | Single Home |

**Source: Regulation & Quality Improvement Authority**

## APPENDIX 4: REGIONAL REPRESENTATION OF RESPONDING NURSING HOMES IN PHASE 2

| Geographical Region | Number of Nursing Homes who Responded to Phase 2 |
|---|---|
| BHSCT Region | 9 |
| NHSCT Region | 8 |
| SEHSCT Region | 11 |
| SHSCT Region | 9 |
| WHSCT Region | 8 |
| **Total** | **45** |

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