All Wales Integrated Care Pathway Project
For Care Homes

“Completing the Audit Cycle”

Retrospective Baseline Audit Findings of Documented Care
During the Last Days of Life of
Residents who died in Care Homes

and the

Re-audit Findings following implementation of the ICP

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Background

It is widely accepted that palliative care should be part of the care extended to patients who have a chronic progressive disease and for whom a cure is not possible (National Council for hospice and specialist palliative care services, 1998) regardless of the care setting (National Institute for Clinical Excellence, 2004). There have been projects in the UK and North Wales addressing the palliative care education needs of Care Home staff but none previously in South East Wales.

The South East Wales Cancer Network, with the support of Macmillan Cancer Support, instigated a project to coordinate the progression of the implementation of the All-Wales Integrated Care Pathway (ICP) for the last days of life into Care Homes (nursing) across the Network area (Nov 2005-Nov 2008). The role of the project Coordinator is to create a system which develops, supports, and sustains the implementation of the All-Wales ICP into care homes.

The National Council for Palliative Care, (2006) states that five deaths in every six are of people aged 65 years or over, and one in every five of all deaths take place in a Care Home which establishes the need for ensuring that Care Home staff are educated and equipped to care for residents at the end of life.

The Welsh Health Circular WHC (2006) 030, formally endorses the All-Wales ICP following the ministers commitment to ensure that health care encompasses the needs and wishes of those at end of life.

The National Institute for Clinical Excellence, (2004;8.13), (NICE) recommends,

“Staff providing general Palliative Care should be trained in identifying needs of patients and carers and in general principles and practices of Palliative Care”

This all supports the project with its aims for ICP implementation.

All Wales ICP Care Home Project Aims

- To coordinate, develop & improve care of the dying in Care Homes throughout Network area through implementation of All-Wales Integrated Care Pathway (ICP) for the last days of life
- Through negotiation with local palliative care providers assist in facilitating the implementation of the ICP into participating homes.
- To create a system which develops, supports & sustains implementation of the All Wales ICP
- To develop an education pack/ facilitated learning pack on the concept and documentation associated with the All-Wales ICP in conjunction with local specialist palliative care providers
- To carry out a baseline audit to examine the documentation of care provided in care homes for dying patients/residents, prior to implementation of the All-Wales ICP
To evaluate the current level of palliative care knowledge and skills held by care home staff participating in the project.

Through negotiation with local palliative care providers assist in facilitating the implementation of the ICP into participating homes.

**To evaluate effectiveness of education through completing the audit cycle one year on from the baseline audit.**

This Report will focus on the audit which was completed in September 2007, at the end of year two of the project. A baseline review was initially completed as a method of examining current practice. This baseline pre-implementation audit was carried out, prior to education on the All-Wales ICP to examine the documentation of care provided in Care Homes for dying patients/residents in their last days of life. The audit of documented care during the last days of life is a measure of the quality of documentation. It must be stated that with clinical governance in practice if care is not documented then in essence, care cannot be measured and the intervention ‘did not take place’.

**Method**

Three “champion homes” were nominated from each Local Health Board (Jan 2006). This was achieved by sending written requests to each Nurse Director from the ten Local Health Boards in the South East Wales Cancer Network area. They were asked to collaborate with their local Trusts and Palliative Care Clinical Nurse Specialists in order to decide which Care Homes would participate.

The Care Pathway co-ordinator undertook visits to these Care Homes between February 2006 and August 2006. The last five sets of deceased resident records were requested in each Care Home. This proved to be challenging at times due to accessibility of notes, or incompleteness of information, e.g. medication charts.

**Baseline pre audit conclusion:**

The audit demonstrated poor recording of care.

The conclusions from the pre-audit concurred that:

- There was poor evidence of communication between the care home staff, patients, relatives, GPs, hospital staff and other involved professionals.
- There was evidence of poor symptom control of dying patients/residents in care homes.
- Care Homes would greatly benefit from a programme of ‘facilitated learning’ on the Foundations in Palliative Care incorporating the use of the All-Wales Integrated Care Pathway for the Last Days of Life.
Developments and Changes Implemented:

Changes were implemented with the collaboration of the CH matrons, LHB’s and the Palliative Care CNS’s including:-

- A Formal education needs analysis of care home nurses in the champion homes was carried out.
- An Education sub-group was formed
- A standardised ICP education pack was developed
- Formal teaching sessions were carried out
- ‘Train the trainer’ syringe driver training was set up and implemented
- Matron forums were set up and established
- Informal training and support sessions, including post-death debriefing sessions were delivered
Re-audit - Sept 2007

To complete the audit cycle and evaluate effectiveness of the implemented changes and developments a re-audit was undertaken between 1/08/07 and 12/09/07 using the same method as the baseline audit.

Table 1 outlines the number of Nursing Homes visited and the number of deceased resident records audited from each of the Local Health Board areas in the South East Wales Cancer Network area in both the pre and post education audits.

<table>
<thead>
<tr>
<th>LHB</th>
<th>Homes visited</th>
<th>No. Notes audited</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre</td>
<td>Post</td>
</tr>
<tr>
<td>Blaenau Gwent</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Torfaen</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Newport</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Cardiff</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Vale of Glamorgan</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Merthyr Tydfil</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>RCT</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Monmouthshire</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Caerphilly</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Bridgend</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Totals</td>
<td>29</td>
<td>29</td>
</tr>
</tbody>
</table>

The Audit tool used was based on the ‘Welsh Collaborative Care Pathway Project’ tool 2000. Results were then collated and analysed using an excel database.

Results

All the Care Homes visited willingly participated in the audit. In all, 130 sets of notes from 29 Care Homes were reviewed over the six month period in the pre audit and 133 sets of notes from the same 29 Care Homes were reviewed in the post audit. Six “Champion Homes” did not have five sets notes available to audit in the pre and post audit (between 1-4 sets notes available to audit). All Care Homes but one has “paper” notes/records, 1 use electronic.
In the pre audit 4/29 Care Homes said they used the All-Wales ICP (questionnaire data). The first Care Home had used one ICP, but the documentation was incomplete and none of the staff had had any formal education.

The second Care Home had used one ICP. The medical assessment had been completed but the nursing assessment had not been completed.

The third Care Home had not used the ICP in any of the reviewed notes. They had suggested its initiation once but the GP felt it was too soon (Patient had died 3 weeks later).

The fourth home had used the ICP for one patient for 12 hours prior to death.

The ICP had been commenced in 3/93 resident records (of those residents that died in the Care Home). Therefore ICP usage was found to be 3% in the pre audit.

In the post audit, 10/29 Care Homes had used the ICP. 28 ICPs had been used and completed. The average length of time residents were on the ICP prior to death was four days. The shortest time was a few hours and the longest was 14 days.

There were two ICPs commenced and stopped when residents did not die and recommenced in one case a few hours before death and in the second case the day before the resident died.

The omissions from the 28 used ICPs were as follows:

- The ‘after death’ page was not used at all in four ICPs, others were not fully completed.
- A few staff continued writing in kardex and duplicating in ICPs
- Not all ICP PRN medications were prescribed; nothing was documented on the variance as to why only certain medications from ICP guidelines were prescribed. The findings included:
  - One resident had no analgesia prescribed (3.5%), was agitated and had sedative prescribed.
  - Eight residents on the ICP did not have antiemetics prescribed (28.5%); none of these has documented sickness as a symptom.
  - Three residents on the ICP did not have sedatives prescribed (11%); none of these had documented agitation as a symptom.
  - Seven residents on the ICP did not have an anticholinergic prescribed (25%); three of those residents had noisy secretions documented as a symptom.
- Variance sheets were not appropriately completed i.e.; used inappropriately as a communication sheet
- ICP document pages not filed together, therefore difficult to follow/ find pages in some cases
ICP usage had gone up in the post audit from 3\% to 31\% as Table 2(also shown on graph) demonstrates, also on chart.

(** denotes the LHB areas that did not have an ICP document in use at the time of the audit.)

Table 2

<table>
<thead>
<tr>
<th>LHB</th>
<th>Number of Homes visited</th>
<th>ICP used pre-audit</th>
<th>ICP’s used post - audit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blaenau Gwent</td>
<td>3</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Torfaen</td>
<td>3</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Newport</td>
<td>3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Monmouthshire</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Caerphilly</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Cardiff</td>
<td>3</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Vale of Glam</td>
<td>3</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Merthyr Tydfil</td>
<td>2 (2 CHs)</td>
<td>0</td>
<td>0 **</td>
</tr>
<tr>
<td>RCT</td>
<td>3</td>
<td>0</td>
<td>0 **</td>
</tr>
<tr>
<td>Bridgend</td>
<td>3</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Totals</td>
<td>29</td>
<td>3/93 (3%)</td>
<td>28/90 (31%)</td>
</tr>
</tbody>
</table>
Graph 1: Demonstrates the percentage % difference between pre and post audit of hospital deaths in relation to ICP usage

Increased ICP usage demonstrates decrease in percentage of hospital deaths in Cardiff, Vale and Blaenau Gwent. (Although there was not an ICP document in use in RCT it was clear in some records that the principles of the ICP were adhered to).
Demographics

In the pre audit of the 130 residents audited, 86 (66%) were female, and 44 (34%) were male.

In the post audit 86 (65%) residents were female and 47 (35%) were male, as demonstrated on Graph 2.

*Graph 2*
**Age Distribution**

The majority of those who died were over 80 years of age in the pre audit with the average age being 86 years.

In the post audit the average age was also 86 years, reduced by the higher number in the under 70 age group. (*see Graph 3*)

**Graph 3**

![Age of All Deceased Patients](image)

**Place of Death**

In the pre audit 37 residents (28%) died in hospital after being transferred from the Care Home, 93 (72%) died in the Care Home itself.

- Length of stay in hospital from date of transfer to date of death ranged from 1.5 hours to weeks
- It was documented that 3/37 (8%) died on all Wales ICP in hospital
- In the majority of cases it was very unclear why the residents were admitted to hospital, What happened in hospital
- Average age of residents that died in hospital 86 years (*ex 56yr old??*)
In the post audit 43 (32%) residents died in hospital after being transferred from the care home. *Graph 4* demonstrates this per local health board.

- Length of stay in hospital from date of transfer to date of death ranged from hours to over six weeks
- 5/43 (12%) died in under 12 hours, 12/43 (28%) died in 12 hours to one week. Times were not clearly documented in other cases
- In the majority of cases it was very unclear why the resident was admitted to hospital or what happened in hospital?
- Average age of Patients that died in hospital was 86 years.

*Graph 4*  Place of Death
Diagnosis

In the pre audit, 17 of the 130 residents (13%) had a diagnosis of cancer. In the post audit, 28 of the 133 residents (21%) had a diagnosis of cancer. Other diagnoses ranged from dementia, CVA, Parkinson’s, heart failure - to ‘old age.’

Evidence of communication

Pre-audit showed that documentation of communication with any resident or family member regarding wishes on hospital admission was negligible. There was very little documented record from hospital on interventions carried out and no documentation from hospital on actual date of death.

Post audit showed that documentation of communication appeared better in cases, documentation overall seemed more “systematic”. There was still little documented record from hospital on interventions carried out and little documentation of communication from hospital on actual date of death.

GP’s were informed in 125/133 (94%) in post audit (88.5% in pre audit) that patient was deteriorating. There was documented evidence that family were informed in 70/133 (53%) in post audit (44% in pre) of cases that the resident were deteriorating.

There was documented evidence that the GP was contacted regarding death in all cases where patient died in the care home as the GP is the death verifier and certifier.

Of the 37 patients who died in hospital in the pre audit, there was no evidence that the GP had been informed of their death: it is assumed that the hospitals do this. The same applied for the 43 residents in the post audit that died in hospital.

Of the 8: 6% in post audit (10: 8% in pre) residents who had any type of clinical nurse specialist involvement, none had been contacted regarding death according to documentation.

Resuscitation Status

In the pre audit 44/130 (34%) patients had documentation to support ‘allowing natural death to occur’.

In the post audit 62/133 (46%) patients had documentation to support ‘allowing natural death to occur’.
**Spiritual Support**

In the pre audit 67/130 had their religious denomination recorded (51%) and there was no documentation to support any level of spiritual support. In the post audit - 71/133 had religious denomination recorded (54%) **BUT** those where the ICP was used had documented evidence of spiritual care and support.

**Primary Symptoms Documented**

In the pre audit 22 residents had it documented that they had pain as a symptom. 10 of those residents had analgesia prescribed.

In the post audit 12 residents had pain recorded as a symptom and all had analgesia prescribed. (Demonstrated on *Graph 5.*).

*Chart 5: Pain*
Chart 6: Agitation

In the pre audit 9 residents had agitation recorded as a symptom and 4 (44%) of those had a sedative prescribed.
In the post audit 16 residents had agitation recorded as a symptom, 9 (56%) of those had a sedative prescribed.

Agitation

Pre (n=9) Post (n=16)

<table>
<thead>
<tr>
<th></th>
<th>Pre (n=9)</th>
<th>Post (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No medication</td>
<td>5, 56%</td>
<td>7, 44%</td>
</tr>
<tr>
<td>Medication</td>
<td>4, 44%</td>
<td>9, 56%</td>
</tr>
</tbody>
</table>

Chart 7: Nausea and vomiting

Nausea and Vomiting

Pre (n=7) Post (n=7)

<table>
<thead>
<tr>
<th></th>
<th>Pre (n=7)</th>
<th>Post (n=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No medication</td>
<td>7, 100%</td>
<td>5, 71%</td>
</tr>
<tr>
<td>Medication</td>
<td>0, 0%</td>
<td>2, 29%</td>
</tr>
</tbody>
</table>
In the pre audit 7 residents had a recorded symptom of sickness but none of those 7 had an antiemetic prescribed.
In the post audit 7 residents had a recorded symptom of sickness and 2 of those had an antiemetic prescribed.

**Chart 8: Respiratory Tract Secretions**

**Respiratory Tract Secretions**

- **Pre audit (n=6)**
  - No medication: 6, 100%
  - Medication: 0, 0%

- **Post Audit (n=13)**
  - No medication: 7, 54%
  - Medication: 6, 46%

In the pre audit 6 residents had a recorded symptom of respiratory tract secretions; none of the 6 had an anticholinergic prescribed.
In the post audit 13 had the symptom recorded and 6 had an anticholinergic prescribed.
Experiential findings

Care Homes can be appropriate settings for the provision of good quality palliative care (Hockley 1991), provided there is an understanding of the principals of palliative care amongst nursing home staff and access to specialist palliative care when required. The project has undoubtedly raised care home nurses understanding of the principals of palliative care through education on the ICP.

The project co-ordinator has spent 2 years working closely with the care home sector across South East Wales and has found key comparables with regard to barriers to the successful ICP implementation.

Where a Care Home had a consistent or established nurse/matron/manager the coordinator found building working relationships more productive.

In 5/29 (17%) “Champion homes” the matrons have moved on from post since project began. Three of those matrons are now matrons in other care homes across the Network area, one has retired and one has resigned. This supports findings from the “Education Needs Analysis” whereby it was found that even if care home staff change jobs they often remain within the care home sector.

One of the “champion homes” has had 4 matrons since the project began; another has been without a matron for many months.

In the homes without a constant lead the coordinator found uptake of education poor and where education has taken place there has been no evidence of ICP usage. In these instances the only follow up on ICP understanding and usage has been one-sided i.e. from the project coordinator.

The matron* is for the most part the coordinators’ “Link Nurse” within the Care Home for taking the lead on organising staff for training and encouraging the use of the ICP.

For successful implementation of the ICP the coordinator has found that Care Home nursing staff must feel confident in their skills at recognising when a resident is in the dying phase. Exploring issues around recognising the dying phase has been found to be very useful to staff. Many have said that they feel more empowered and “less apprehensive” about discussing issues regarding the end of life of their residents.

The coordinator found a large part of discussion in the education sessions focused on the difficulties Care Home nurses face with the dementia/general frailty illness trajectory. From the discussions during the education sessions it was clear that the care home nurses are the best placed to recognise when a resident is dying.

The lack of protected time for education has been highlighted by some as a barrier to implementation but the coordinator found that through having a learning contract with the care homes involved and by delivering the sessions in the individual care homes, only a few sessions were cancelled.
Some of the community specialist palliative care teams have an established link with some of the care homes and ongoing education/training could be built in to encourage/sustain ICP usage.

These experiential findings are comparable to a survey carried out by Froggatt et al (2002) where they found through a survey of 730 community specialist palliative care nurses that whilst 92% of them had worked with care homes that the work was primarily reactive and undertaken infrequently.

In the pre audit there was documented evidence of community palliative care specialist nurse input in 10 residents (8%). In the post audit there was documented evidence of input in 8 resident’s records (6%).

Care home staff would welcome and benefit from closer ongoing long term collaboration with their community palliative care clinical nurse specialists.

**Conclusions and Recommendations for the future**

The re audit demonstrated an improvement in the recording of end of life care. The all Wales ICP use has increased from 3% to 31% in one year.

Where the ICP was used in the post audit there was a reduction in hospital deaths as demonstrated on Graph 1 in Cardiff, Vale of Glamorgan and Blaenau Gwent (also noted in RCT where there was no ICP document available to use but the principals of the ICP were adhered to).

There remains poor documented evidence of communication between care home staff, patients, relatives, GPs, hospital staff & other involved professionals. The pre and post audit demonstrated poor recording of care.

The care homes main link for expertise/specialist advice is through the GP, but it is widely recognised that the support and advice received can be inconsistent. The palliative care educational needs of GPs should therefore also be addressed if appropriate end of life care is to be provided for all care home residents across the network area.

Care home residents should have the same access to specialist palliative care teams as other residents/patients. This can be achieved through formal liaison, ongoing education and an increased presence/contact of teams in the care home sector.

The project coordinator will ensure that by the end of the project every care home involved with the project has a named community palliative care clinical nurse specialist with clear guidelines for referral. This will be achieved through collaboration with the teams.

There also remains the ongoing issue for the care homes of accessing the ICP document. One of the 10 LHBs has an electronic version of the ICP which makes access for the care homes easier. The project coordinator will clarify ongoing access
of the ICP for the care homes over the forthcoming months, ensuring a system to sustain usage is set up.

Care Homes would greatly benefit from ongoing education on the foundations in Palliative care incorporating use of the All Wales Integrated Care Pathway for the Last Days of life.

The biggest challenge will be sustaining ongoing use of the ICP; the project has a life cycle with 10 months remaining in which time systems to sustain usage will be addressed.

This will include formalising work with CSSIW to influence the care of the dying standard incorporating use of the ICP further enforcing the WHC 030 to endorse implementation.

The project will circulate project recommendations at the end of the project cycle in October 2008.
References


National council for hospice and palliative care services, 1998