

Patient Identifier

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SECTION 2: ONGOING ASSESSMENTS

S2.1 Assessment of pain 4 hourly/each visit	Yes	No
S2.2 Was the patient in pain	Yes	No
S2.3 Was prn analgesia given	Yes	No
S2.4 Assessment of nausea & vomiting 4 hourly/each visit	Yes	No
S2.5 Was nausea & vomiting a problem	Yes	No
S2.6 Was prn antiemetic given	Yes	No
S2.7 Assessment of Agitation 4 hourly/each visit	Yes	No
S2.8 Was agitation a problem	Yes	No
S2.9 Was prn sedation given	Yes	No
S2.10 Assessment of excessive respiratory secretion 4 hourly/ each visit	Yes	No
S2.11 Was excessive respiratory secretions a problem	Yes	No
S2.12 Was prn anticholinergic given	Yes	No
S2.13 Assessment of mouth care 4 hourly/each visit	Yes	No
S2.14 Assessment of Micturition problems 4 hourly/each visit	Yes	No
S2.15 If pressure relieving aids required were these provided	Yes	No
S2.16 Assessment of Bowel Care 12 hourly/each visit	Yes	No

CARE AFTER DEATH

S3.1 GP/Locum Service contracted re patients death	Yes	No	
S3.2 Post mortem discussed	Yes	No	Not applicable
S3.3 Special needs identified/religious/infection needs	Yes	No	
S3.4 Family/other informed of tasks following death	Yes	No	
S3.5 Appropriate documentation given to family/other	Yes	No	

¹ © LCP Project Team at the Marie Curie Palliative Care Institute, Liverpool.

Patient Identifier

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COMFORT MEASURES

1.1	Pats current medication and non essentials discontinued			Yes	No		
1.2	If other medication not discontinued was a documented reason given			Yes	No		
2	Was as required (PRN) prescribed subcutaneously:	2.1 Analgesic	Yes	No	2.2 Antiemetic	Yes	No
		2.3 Anticholinergic	Yes	No	2.4 Sedative	Yes	No
2.5	If yes were drugs perscribed the ones recommended in your local formulary guidelines			Yes	No		
3	Were the following interventions discontinued	3.1 Blood Tests	Yes	No	Not applicable		
		3.2 Antibiotics	Yes	No	Not applicable		
		3.3 Intravenous Fluids	Yes	No	Not applicable		
3.4	Were do not resuscitate instructions documented	Yes	No	Not applicable			
3.5	Were instructions re do not transfer to hospital documented	Yes	No	Not applicable			
3a	Were inappropriate nursing interventions discontinued:						
	3a.1 Routine Turning Regime	Yes	No	Not applicable			
	3a.2 Taking vital signs	Yes	No	Not applicable			
3b	Was a syringe driver set up within 4 hours of prescription	Yes	No	Not applicable			

PSYCHOLOGICAL/INSIGHT ISSUES

4	Ability to communicate in English Assessed	Yes	No	Not applicable
5.1	Patient aware of diagnosis?	Yes	No	Not applicable
5.2	If no is there a documented reason	Yes	No	
5.3	Patient aware s/he is dying	Yes	No	
5.4	Next of kin aware patient is dying	Yes	No	

RELIGIOUS NEEDS

6.1	Patients religious needs assessed	Yes	No	Not applicable
6.2	Patients religious needs met	Yes	No	Not applicable

COMMUNICATION WITH FAMILY - OTHERS - PRIMARY HEALTH CARE TEAM

7	Identified how family/others were to be contacted/ informed of patients impending death?	Yes	No	Not applicable
8	Family/others given written information re facilities	Yes	No	Not applicable
9	Patients GP/locum service aware that patient in dying phase	Yes	No	Not applicable
10	Patients plan of care discussed with family/others	Yes	No	Not applicable

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APPENDIX 2

The Integrated Care Pathway (ICP) Project

Information Sheet for Relatives taking part in Interviews

The Integrated Care Pathway project is the final phase of a five year research project funded by St Columba's Hospice in Edinburgh. The project was set up originally as an educational initiative to support nursing homes in Lothian. Because of changes in the health service and the increasing number of older people in the population, there are increasing numbers of people dying in nursing homes. Staff taking part at the beginning of the research said that a care plan that would guide them in the best way to care for their residents at the end of life would be helpful. The integrated care pathway for the last days of life is therefore now being implemented in eight nursing homes in Lothian who have volunteered to take part in the project.

As part of the evaluation of the integrated care pathway we would like to interview relatives of residents who have died in nursing homes. We are interested in hearing your story and learning about the things that you thought went well at the time and that helped you to cope.

If you agree to take part it would involve being interviewed by myself, the research assistant on the project. The interview would take place at a time convenient for you, either in your own home or wherever is easiest for you, and would last between half an hour to one hour. With your permission the interview would be tape recorded so that I do not need to take notes and can concentrate more easily on what you are saying. Taking part in an interview is entirely voluntary. If you decide, even during the interview, that you do not want to continue you can stop at any time.

If you have any questions or would like more information please do not hesitate to contact me at St Columba's Hospice Telephone 0131 551 1381 Ext 168

Julie Watson
Research Assistant

APPENDIX 3

Evaluation of the Implementation of the Integrated Care Plan (ICP) for the last days of life

CONSENT FORM (Relative)

.....I, am
willing to take part in this interview. I am happy for our discussion to be taped. I know that I can withdraw
at any point during the discussion, and that if there are any problems that arise from this interview I
know I can phone Julie on the above number for further advice.

Signature

NAME

.....Date

APPENDIX 4

Relatives Interview Outline

How long was ...in the NH

How did you feel about the way the staff talked to you when they thought he/she was becoming more poorly and dying?

Did you realise he/she was dying?

Was the word dying ever mentioned by anyone?

Were there opportunities to sit down and chat to the staff?

How well did you feel prepared?

Tell me a bit about what the staff/GP told you about during that time and afterwards

Tell me a bit about how.....was in the last few days.

What about other aspects other than physical care – the spiritual care, the psychological care that your...received...can you tell me a bit about that?

What if anything particularly distressed him/her

Do you think he/she knew they were dying?

Were you able to speak about dying?

What were your needs at the time?

Tell me about how your needs were addressed

How were you supported?

Were you asked about your particular needs?

Would you have wanted that?

Would that have helped? If so in what way?

How did you feel it was talking to staff about dying/your loved one?

Tell me about what way you were involved in decisions that were to be made or about the care ...received

Is there anything else you would like to say that would help us to learn about caring for residents dying in nursing homes?

APPENDIX 5

Values Clarification Exercise

Your thoughts and beliefs about End-of-life Care

<p>I believe the purpose of good end-of-life care is</p>
<p>I believe good end-of-life care can be achieved by</p>
<p>I believe my role in caring for dying residents is</p>
<p>I believe the factors which enable good end-of life care to occur are</p>
<p>I believe the factors which inhibit good end-of- life care are</p>
<p>Other values and beliefs about the care of dying residents I have are</p>

APPENDIX 6

Managers Interview Outline

How do you think end-of-life care in nursing homes has changed over the last ten years?

How do you feel about caring for residents at the end-of-life?

3a. What is your opinion about end-of-life care in your nursing home at the moment?

b. What would you like to see happen with end-of-life care in your home?

4a. What do you see as your role in the ICP project?

b. Is there any way the project can support you in this role?

5. How do you find bringing about change in this home?

6. How would you like to have feedback from the project?

APPENDIX 7

What is it like to work in your organization' questionnaire (Bates, 1994)

Please look through the list of statements below and circle the number on each continuum that you think best describes your place of work.

Nursing Home:Your job title:

a	People I work with don't have shared values, interests & beliefs	1 2 3 4 5	People I work with have shared values, interests & beliefs
b	People I work with break rank & go it alone	1 2 3 4 5	People I work with pull together and work as a team
c	There is conflict between the people I work with	1 2 3 4 5	There is harmony between the people I work with
d	Problems that arise are dealt with in an 'ad hoc' way	1 2 3 4 5	We respond to problems in a coherent & systematic way
e	Our work is governed by standards from the past	1 2 3 4 5	Our work is guided by a vision of the future
f	Where I work there are winners and losers, 'them and us'	1 2 3 4 5	Where I work people confront and move beyond their differences
g	We fear change	1 2 3 4 5	We embrace change
h	Communication between the people I work with is poor	1 2 3 4 5	Communication between the people I work with is good
i	Our team is inward looking	1 2 3 4 5	Our team is outward looking
j	Our team is dominated by routine and by systems	1 2 3 4 5	Our team is creative and ideas dominate
k	People I work with don't reflect on their work	1 2 3 4 5	People I work with reflect on their work

Many, many thanks for your time. Julie Watson, St Columba's Hospice. 0131 551 1381

APPENDIX 8

SCENARIO – ‘ICP’ TEACHING

Molly Stevens is a 97-year old lady who has been at Shadowland Nursing Home for 18 months. She has a 95-year old husband who manages to look after himself in a ground floor, sheltered housing flat in Stockbridge. He used to visit everyday but now visits 2-3 times a week because of being frail. They have a son who is married and lives in Dunbar. Their other child is a daughter who works as a GP in Newcastle-upon-Tyne. She is not married.

Molly required admission from sheltered housing because of increasing ‘wandering’. Her short-term memory has been very poor and made worse after being hospitalised following a fracture of her left femur 4 months ago. On returning to the nursing home she became increasingly irritable and difficult to care for. After assessing and managing her pain Molly was much more comfortable although very frail indeed. Her medications have been: Ibuprofen 200mg/6hrly, Co-codamol 30/500mg ii/6hrly, Lactulose 20mls bd, Senna ii/nocte, and Welldorm i/nocte.

Over the last 7 weeks however, Molly has deteriorated further – she has had a couple of chest infections which have been treated with antibiotics. She does not appear to be so hungry – can easily be tempted with puddings etc. but noticeably eating less. Over the past two weeks Molly has hardly eaten anything. She has become more gaunt. She sometimes will take fluids but this has become increasingly difficult. A fluid chart has been started. The daughter is visiting every other week-end and has specifically asked the carer if she can speak with the GP. She feels her mother’s condition is deteriorating.

Monday, 21st June (afternoon) – After the week-end the nurse speaks to Molly’s GP surgery requesting a visit because of Molly’s deterioration. Later that afternoon Molly is being helped on to the commode in her room by Gail (senior care assistant) who knows her very well. Molly repeats, ‘It’s enough....enough...enough!’ The care assistant hears what Molly is saying and replies, ‘Enough of what, Molly?’ Molly just repeats ‘enough...enough’. Molly sits on the commode but after ten minutes hasn’t managed to use it and is helped back to bed. The carer intuitively wonders whether Molly is talking about ‘enough of living like this’ and speaks with the staff nurse who records the event in Molly’s care plan

Tuesday, 22nd June (morning) – GP visits as promised. He chats to the staff nurse and then they both go and see Molly. Overnight she has become more restless and groans. The GP listens to her chest and feels her pulse. She is hot to touch. He tries to speak with Molly but gets no real response other than Molly just staring at him with the occasional moan. She looks very cachectic and dry. The GP and nurse leave the room and discuss the situation. ‘I am wondering whether we shouldn’t try an antibiotic? She’s definitely got signs of a chest infection. What do you think?’ he asks the staff nurse. ‘Well, I am not sure whether that is appropriate. Molly is 97 years old. Just yesterday she was saying to the care assistant...."enough....enough". I am not sure what that was about but I wondered whether she was asking us to let her die. Would you like to speak with the daughter in Newcastle? Do use the phone in the office! Also, I am thinking she may be in pain – at times she is not able to take all her tablets?’ The GP agrees to discuss the situation with the daughter and phones the daughter from the nursing home.

‘I think you are right, staff! Having spoken with the daughter – perhaps we should concentrate on making sure Molly is comfortable and forget the heroics.’ The staff nurse replies, ‘You mean you think

she is dying?' Both the GP and the staff nurse agree together she is dying and the nurse reminds the GP that the ICP (Integrated Care Pathway) for the last days of life needs to be started. Then they turn to the 'initial assessment' pages of the ICP. They discuss Molly's restlessness and inability to swallow all her medication. They decide to discontinue her oral drugs and start a syringe driver with Diamorphine 5mg + Methotrimeprazine 12.5mg to run over 24hrs. The staff nurse asks the doctor to prescribe Indomethacin supps prn incase Molly's bone pain is not totally controlled by the morphine in the syringe driver. Molly has always had Bisacodyl supps prn if she became constipated so they decide to keep those on the prescription. The GP also prescribes 'Buscopan prn' in case Molly develops a 'rattly' chest. The GP thanks the nurse for her help and leaves the nursing home at 2pm in time for his afternoon surgery. The staff nurse makes sure the prescription gets phoned through straightaway so that the drugs can be started as soon as possible.

Just as Gail is going off duty she pops her head into the staff room to tell the report that Molly has been transferred to a spenco mattress and bedsidess put on the bed but not pulled up. As the staff nurse continues to report back about Molly she suggests that the nurse in charge of Molly's care on the 'late shift' phones Molly's minister who has always visited regularly and tell him it is thought that Molly is dying. "If the son doesn't visit that evening then he too needs to be spoken to about the change in Molly's condition." **[complete pages 3, 5 & 6 + 9].**

June 22nd (afternoon) – The newly qualified staff nurse in charge of Molly's care has never come across an ICP before. She reads the notes and Sue (care assistant) helps her to understand what has to be done. They turn to Section 2, and go together to Molly's room to complete the sheet for 14.00hrs.

When they arrive up in Molly's room, Molly has her legs over the side of the bed and is restless. The new staff nurse is aware that sometimes restlessness can be because of pain but also because of constipation or a full bladder. She asks Sue whether Molly has had her bowels opened. Sue confirms she had a bowel motion two days ago but explains that Molly's pads were 'dry' this morning + during the night. The staff nurse and Sue help Molly back into the middle of the bed. As she does this, the new staff nurse takes the opportunity to see if Molly's bladder is full. She puts her fingers over where the bladder is positioned and taps carefully with the other hand. There is a definite sound of fluid present in the bladder. While the staff nurse goes to get a catheterisation pack, Sue offers Molly some water and then cleans the mouth from the mouth tray and waits for the staff nurse to return. Directly the bladder is relieved of its 1 litres of urine, Molly settles and appears very comfortable. The care assistant went back again regularly making sure that Molly was comfortable. At 18.00hrs she did all the next 4hrly checks. All was well **[complete page 7 for 16.00hr & 20.00hrs + variation sheet, page 12].**

Meanwhile the staff nurse was sorting out the medicines from the pharmacist. They had arrived at 18.00hrs and the syringe driver was made up with the Diamorphine and Methotrimeprazine and set in place. At 19.30hrs the telephone rings and it is Molly's son – he has just heard about Molly's deteriorating condition. He asks her if he needs to visit tonight. The new staff nurse confirms that Molly is now very comfortable and at present her condition is stable but that he can phone at anytime. They agree that he will contact them before he goes to work in the morning and if all is well will be in to see his mother at 4pm after his important meeting.

Just as she is about to go home, the new staff nurse realises that she hasn't signed the ICP for the medications given. On reading the ICP she realises that she needs to have made up a syringe driver chart. She doesn't know where to find one until the care assistant tells her that she thinks there is one at the end of the ICP notes. She finds it and completes it; she is very pleased that this ICP thing is a 'team effort'. She then shows the chart to the night nurse taking over the care and shows her where

she needs to complete things. **[complete page 8 + interdisciplinary communication – page 9].**

Molly has a very comfortable night – with nothing new to report. **[complete pg 7 & 8]**

Wednesday, June 23rd (morning) – Gail is caring for Molly to-day. At 08.15hrs, before seeing to the breakfasts, she goes in to see how Molly is. She is peaceful but rousable. Gail decides to help Molly with a little drink if she is able, clean her mouth and change her position, but wants to come back to do her full care after she has helped her two other residents to have a bath. As she turns Molly with the help of another carer she notices that the catheter is draining urine properly [complete pg 7]. At 09.30hrs the minister of Molly's church arrives to see Molly. Gail feels bad that she hasn't had a wash but at least her mouth is clean and she looks comfortable. Gail and another carer return at 10.30hrs to give her a nice wash. They offer some fluids but Molly pushes away the beaker [complete pg 7 + pg 8/9 re minister].

June 23rd (afternoon) – When the afternoon shift go in to see Molly at 14.30hrs they find her restless. They call the staff nurse Clair who knows Molly very well. Clair looks at the ICP and Molly's drug kardex. She is wondering why Molly is restless. She is not in retention since she has the catheter. She also had her bowels well opened 3 days ago so that shouldn't be worrying her. Clair wonders whether it could be pain – Molly has started the syringe driver so why is it not working? Clair remembers how much the Ibuprofen helped Molly's bone pain but of course she is unable to swallow so that has been discontinued. She then notices that Molly has been written up for some prn Indomethacin supps. Clair is convinced that giving an Indomethacin supps will help but decides to phone the GP for confirmation. He is happy for her to go ahead with the Indomethacin and is relieved the drugs is written up and ordered already so he doesn't have to make a visit. At 18.00hrs Clair goes to see Molly – yes! She is sleeping peacefully. Clair hands over again to the same night nurse who was on last night. **[complete pg 7, 8 & 9]**

All is well until the care assistant reports to the night staff nurse at 02.00hrs that Molly's breathing has become noisy and wet. She records it as a 'variance' on the chart and then gets the night staff nurse to write up the variance on pg 12. In filling in the chart the staff nurse is reminded about the two nights she did at the hospice. A patient at the hospice had become very 'chesty' and the sister there had given some Hyoscine to help stop the rattle. Perhaps the same could be given in this situation. The night nurse gets Molly's chart. She looks at the prn medication – Indomethacin Supps prn, and s/c Buscopan were prescribed. She didn't know what the drug 'Buscopan' was so looked up in the MIMMs book that was in the treatment room. To her surprise she realises it is similar to the hyoscine that she had seen work so well in the hospice. She read at the side of the prescription – to be given for 'rattly chest'. She decides therefore to give one dose to see if it helps Molly's chestiness since she thought it might be quite distressing for the family when they visit the next day – especially if it gets worse. **[complete variance page 12]**

Thursday, 24th June (morning) – When Gail goes into see Molly at 10.00hrs Gail can tell immediately that Molly has deteriorated over the night. Molly now has shallow respirations and there is mottling on her legs and her hands are cold. Gail gets the deputy matron since the staff nurse in charge is an agency nurse and she wants to speak to someone who knows Molly. Viv (the deputy matron) gladly comes up with Gail to see Molly. Viv again notices a huge deterioration. Viv and Gail together discuss how to care for Molly that morning. She needs a wash as it certainly smelt as though Molly had had her bowels opened. Viv suggests that Gail should wash and change the bed as soon as possible with another carer. Meanwhile she will go and phone the daughter and son, and also the GP. Viv is also very aware that Molly's husband has not visited since Monday. She would see whether the son could collect him from the sheltered housing complex on his way to the nursing home; or, at least, if the husband didn't want to come that he had been told that Molly's condition was now very poor. Viv asks Gail to make sure that Molly isn't in any pain when being washed and turned. **[complete pages 7, 8 & 9]**

At 14.00hrs Gail was sitting with Molly having completed her work when Molly's husband and son appear. She gets up and pulls over a couple more chairs sitting down with them to chat. She speaks openly about Molly's condition – that she is very comfortable, that there is no pain and suggests that they might like to hold her hand and tell her that they are here. Gail warns Molly's husband that her hand might feel quite clammy and cold. Gail stays to chat for a few minutes. She remarks on the slight 'wetness' of the chest and tells them that Molly has been given something for it during the night. She then suggests she will leave them while she gets some coffee for them both. Before she goes she shows them how to ring for assistance if they are worried about Molly.

Before going home at 14.15hrs Gail pops her head into Molly's room. Gail is now off for two days but wanted to come and say 'goodbye'. Molly's husband is still there – he is alone as the son has gone to get his sister. Gail chats briefly and then goes over to touch Molly to say a quick 'goodbye'. She wasn't sure whether the husband realised Molly would not be around when Gail came back on duty – but at least he was there. She left feeling sad but pleased that everything possible was being done in the caring not only for Molly but for the husband, the son and daughter.

June 24th (afternoon) – Viv pops in to see Molly as she is about to go home at 4pm. As she enters the room she sees that Molly's respirations are now very laboured. The husband is sitting there next to Molly but doesn't seem to be registering how near to death Molly now is. Viv could easily just have left the room and pretended she didn't notice; but, she didn't. She stays despite it being time for her to go off duty. She draws up a chair beside the husband and gently gets into conversation. She then starts to speak of how she thinks Molly is very close to 'leaving us'. Molly's husband seems surprised. Viv leans across and feels Molly's pulse – it is thin and thready. What with this and the very irregular respirations with long gaps between each breath, Molly was imminently going to die. She was so peaceful. Viv felt it was important to relay her thoughts which she did. As they sat there together it felt right.....just Molly, her husband and Viv. Gradually the respirations stopped and Viv gently confirms to the husband that Molly has died. Tears well up in his eyes and he pulls out his handkerchief. Viv feels it is such a privilege to be present. They sit and chat for a few minutes and then Viv says she will go and get Clair to take over.

Clair arrives back and she gives Molly's husband a hug. It was a natural thing to do – none of this stiff professionalism - 'feelings' are so important. She knew there was paper work to be done but spending time with someone was also important. Gradually after a few minutes it seemed right to suggest Molly's husband might like to go and have a cup of tea in the Pink Lounge while Molly sorts things out and tidies the room. It was a pity that the son and daughter were not present but in many ways appropriate it was just Molly and her husband.

Clair informed the GP practice that Molly had died and at the same time had been able to contact the son. Molly had always been such a practical person. When she arrived at Lennox House she had insisted that all the necessary 'paperwork' concerning her death should be done now rather than any awkwardness when she became more frail. The home knew her wishes – to be buried in the family grave at Greyfriars Church. Some of the detail of the verification of death on the ICP could be completed now – but a lot of it would need to be done over the next two days. As she looked down it she noticed the 'bereavement booklet' that a few of them had put together. She thought it important to give that to Molly's husband before he went to-day, otherwise he might not get it. She would take it to him straight away. Molly's son wanted to give his last respects to Molly and both he and the husband went in again before they left. The daughter would not be coming in but would 'view' her mother at the funeral premises the next day. Once Molly's husband and son had left, Gail and one of the new carers did the last act of caring – what used to be called 'the last offices'. It was a privilege to do. Clair meanwhile sorted out the notes and completed the 'after a death' form as much as she could. She would need to wait 'til tomorrow before she could fax it through to the management. After that she would return the ICP to the notes. **[complete 8 & 9 + page 11].**

A SIMILAR SCENARIO WAS USED FOR CARE ASSISTANTS BUT WAS SHORTER AND DID NOT DEAL WITH MEDICATIONS

APPENDIX 9

INFORMATION SHEET FOR STAFF

The implementation and concurrent evaluation of the introduction of an integrated [ICP] care pathway for the last days of life, for residents dying in nursing homes in Lothian.

Your nursing home has responded to a practice development initiative, funded by St Columba's Hospice, to pilot the implementation of an 'integrated care pathway (ICP) for the last days of life' for resident's dying in nursing homes [NHs] across Lothian. Eight nursing homes are taking part. An ICP is a tool that helps to guide quality care. Caring for a resident who is dying is often complex especially when we are trying not only to meet the holistic needs of the resident and organising appropriate symptom control, but also addressing the needs of the family and other residents in the nursing home.

There are three of us working with you. Jo Hockley is responsible for helping specific nurses (who we are calling 'change agents') within each nursing home to implement the ICP documentation; Julie Watson is carrying out an evaluation of the whole project; and, Belinda Dewar is supporting the change agents through action learning sets. The 'change agents' need your help and may well ask a few of you to be part of a core team to take this project forward.

The project begins in October 2003 and will end during the summer of 2004. Before you start using the ICP documentation a baseline of current care will be evaluated by Julie in order that changes resulting from the implementation of the ICP for the last days of life can be monitored. The final evaluation will help you judge whether or not the implementation of the ICP documentation is of value to you in caring for residents who are dying.

What is to be expected of you?

Group Interview

The first task is to help you to talk through the things that you think are important when you are caring for someone who is dying. Julie will hold one or two 'group interviews' in each NH. They will last around one hour and will take place in November. At these groups people will be asked to work through thoughts and beliefs about end-of-life care (see attached sheet). This exercise will help you to clarify what you think as a team is important in the care of dying residents. The group interviews will be repeated towards the end of the project once the ICP has been implemented and is 'up and running'. One of your nurses involved in implementing the ICP will hopefully be helping Julie with these groups. Permission will be sought for the sessions to be tape-recorded.

Observing/looking at practice

To help understand more fully the care given to residents who are dying, Julie will look at current documentation including care plans, drug charts and continuation sheets. She will also sit in on some of your hand-overs and observe the work while helping on a shift. Once the ICP has been implemented further observation will take place in order to evaluate any changes in end-of-life care that might have occurred. Looking at practice can be a bit scary and we need to learn together. Before Julie reports on what she is seeing she will always discuss it with you.

Interviews

Individual interviews will take place with nurse managers and GPs attending residents at the NH to get their perspective on end-of-life care. Interviews with relatives of residents who have died in the nursing home will be important and again it is hoped that a staff member involved with implementing the ICP will help Julie with these. Permission for interviews to be tape-recorded will be sought so that Julie can have them as a back-up rather than be scribbling things down through the meetings. At the end of the project all tapes will be destroyed.

Culture Questionnaires

A questionnaire that helps us to understand a bit more about the workings of your organisation will be given to every staff member and we would be most grateful if you would fill these in as soon as you receive them. This questionnaire will be repeated at the end of the study in order to assess whether working together with the implementation of the ICP has affected the culture within which you work.

What is in it for you?

We hope that you will be able to see that there will be gains for you in participating with this project. Sometimes we can get so caught up with the day to day care that making the time to focus on an area of care is difficult. However, by focusing on the implementation of the ICP for the last days of life we think this will enable you to enhance your skills in end of life care for your residents and their families.

Useful links will be made between your nursing home and St Columba's Hospice/Queen Margaret University College (QMUC). Hopefully there may be opportunity for you to access courses at the hospice/QMUC that might be of interest in the future.

Because there are seven other nursing homes taking part, this will enable a 'linking up' and an opportunity to share practice. Obviously much of this sharing of practice will in the first instant be for those nurses acting as 'change agents'. However, as the project progresses there could be opportunities for nurses/carers to share their experiences of the project in a newsletter between the homes.

Consent

Consent will be sought from those contributing to the data being collected in the evaluation. Confidentiality and anonymity will be assured. Although Belinda, Jo and Julie will know details of the nursing homes and carers involved no names will be identified. However, even though no names would be mentioned, sometimes one can still identify the home/person concerned. In this case Julie would always check back to see if you were happy for the data to be used. Julie will be continually checking that any information that has been collected is correct. You will have an opportunity then to discuss whether or not that is an accurate picture of how care is given. Results of the evaluation will be fed back to you both informally and formally.

Your decision to take part in the evaluation aspect of this project (ie being interviewed or agreeing to have Julie working with you) is entirely voluntary and if you don't want that involvement please just say so. Even if at the beginning of the evaluation you have wanted to be involved and then change your mind you have the right to withdraw if you should so wish.

Please don't hesitate to contact us, or the 'change agents' in your nursing home, if you want anymore information. If you would like to take part please sign the consent form attached and place it in the brown envelope on the board.

Belinda Dewar, Development & Research Manager, Centre for the Older Person's Agenda, QMUC, Edinburgh (Tel: 0131 317 3575)

Jo Hockley, St Columba's Hospice, Edinburgh (0131 551 1381 x 168)

Julie Watson, Research Assistant, St Columba's Hospice, Edinburgh (0131 551 1381 x 168)

APPENDIX 10

Evaluation of the Implementation of the Integrated Care Plan (ICP) for the last days of life

CONSENT FORM (staff)

.....I, have
read the information sheet about the evaluation of the implementation of the integrated care plan (ICP)
for the last days of life and am willing to take part as a member of the caring team at XXXXX. I know
that I can withdraw from the evaluation at any time.

Signature

NAME

.....Date

APPENDIX 11

FINAL GROUP EVALUATION

1. What have you learnt from being involved in the project over these last 9 months?
2. How has the project influenced you as a person and/or the nursing home in relation to care of the dying?
3. What do you do now when caring for dying residents and/or their family that you didn't do before the ICP project? Or, anything as a team ? Or, anything as a NH?
4. What have been the difficulties in implementing this ICP?
5. What has helped to implement the ICP? What's helped you to make this change? What would you have liked more help with?
6. What has it been like trying to fit the project in to everyday life in a NH? Has it felt a burden being part of the project?
7. How do you view 'change' having taken part in this project?
8. What aspect/s of the ICP documentation has been the most helpful to you in caring for dying residents/families?
9. What's been difficult in using the ICP documentation?
10. How has it been for you having more responsibility for end-of-life decision making?
11. Are there any draw backs/weaknesses about the ICP documentation?
12. How would you feel if the ICP became a permanent way of documenting the care given to dying residents/families at NH?
13. Would you recommend it to a friend who was working in another nursing home?
14. What would help you to keep using the ICP documentation?
15. Is there anything that would make it difficult for you to continue using the ICP?
16. Is there anything else anyone would like to add?

APPENDIX 12

Key Champions Interview Questions

1. Can you describe how being a key champion in this project has been for you?
2. How has this experience compared with your initial expectations?
3. Are there any specific changes/ developments professionally that have come about in you as a result of being a key champion?
 - How has being a key champion influenced your care for dying residents and their families?
4. What has helped you as a key champion to implement the ICP?
5. What has hindered you in implementing the ICP?
6. What two things have been most useful in the ICP project?
7. What two things are most useful about the ICP documentation?
8. Looking back, would you have done anything differently?
9. How do you think the culture around the care of the dying in your NH has changed or been influenced?

APPENDIX 13

Managers Post ICP Questionnaire

How has the experience of being part of the ICP project compared with your initial expectations?

Have there been any significant changes in you and/or the wider organisational culture of your nursing home as a result of the ICP project? If so can you describe what they are?

In what 2 ways (or more) has the ICP project developed staff in your nursing home?

What do you think, from the nurse manager's involvement, could have been done differently in the ICP project?

What gaps in end of life care has the project highlighted for your home?

How easy do you think it will be to sustain the focus on end of life care in your nursing home? (Please circle the most appropriate answer).

Very Easy 0 1 2 3 4 5 6 7 8 9 10 Very Difficult

What sort of things will help you to sustain the focus on end of life care?

What sort of things will get in the way?

What aspects of end of life care might you plan to take forward in the future?

Has your attitude about death and dying in nursing homes changed as a result of the project? If yes, in what way?

How do you think the culture around the care of the dying in your nursing home has changed or been influenced?

What do you think as a nurse manager has been most useful about taking part in the ICP project?

APPENDIX 14

AUDIT QUESTIONNAIRE

[with the result of 'frequencies' ADDED from all questionnaires returned

TRAINED STAFF QUESTIONNAIRE

	This is a feature of care in this unit...				Effects of the ICP Project		
	All/most of the time	Some of the time	Rarely if ever		The ICP project has had no effect on this	The ICP project has helped us do it better	We've only done it since the ICP project began
PRE DEATH							
The naturalness of dying in old age is openly acknowledged in our unit					30%	67.5%	2.5%
New staff are prepared for caring for dying residents in their orientation					27.7%	60.7%	11.6%
Residents who may want to speak about death and dying are allowed to do so and we do not try to avoid this subject					30.5%	65.3%	4.2%
Giving false hope to a dying resident or family would be challenged in our unit					38.4%	57.1%	4.5%
Staff know when to stop inappropriate interventions e.g. getting people up/dressed when they are too frail.					39.1%	58.3%	2.6%
There is in depth discussion and agreement about when a person is dying <ul style="list-style-type: none"> ● Within the nursing home team ● With GP colleagues ● With the family ● With the resident 					8.3%	75%	6.7%

The goals of care when a resident is dying are understood and we aim to achieve them						14.2%	84.2%	1.7%
** Residents/families wishes are sought and respected regarding end of life decisions... <ul style="list-style-type: none"> ● The use of antibiotics ● Transfer to hospital 						30.2%	69.8%	–
The team are confident about recognizing when somebody is dying						32.2%	64.3%	3.5%
Staff keep their palliative care knowledge up to date						13%	80.9%	6.1%
Each resident and their death is treated as unique						29.4%	67%	3.6%

PLEASE TURN TO 'During the Dying Phase' – overleaf

[** denotes questions omitted from questionnaire to care assistants]

DURING THE DYING PHASE	This is a feature of care in this unit...			Effects of the ICP Project		
	All/most of the time	Some of the time	Rarely if ever	The ICP project has had no effect on this	The ICP project has helped us do it better	We've only done it since the ICP project began
A high standard of physical care is given and adapted accordingly to the changing needs of the resident				36.4%	62%	1.7%
We have access to and/or know where to access the right equipment to support the resident who is dying e.g. pressure relieving mattresses				52.2%	47.8%	–
We have a shared plan of care and shared goals when somebody is dying				21.2%	75.2%	3.6%
We regularly assess for symptoms such as <ul style="list-style-type: none"> ● Agitation ● Pain ● Rattly chest 				20.9%	76.5%	2.6%
**We have knowledge of different medication that can be used in the last days of life				11.6%	79.1%	9.3%
**We anticipate the symptoms residents y have when they are dying				17.5%	70%	12.5%
**We have PRN medication available when someone is dying				19.5%	61%	19.5%
We understand the dying process and the problems that residents might have e.g. not being able to swallow				29.2%	67.3%	3.5%
Our residents die without pain or distress				75.2%	75.2%	–

Our residents have their spiritual and emotional needs addressed						31.3%	67.1%	2.6%
We ensure there is always somebody sitting with an imminently dying resident						53.5%	44.7%	1.8%
We are able to put forward a case to management about the staffing levels to meet the changing needs when a resident is dying						51.8%	45.5%	2.7%
Staff assess the support needs of relatives						38.2%	60%	1.8%
**We are able to strike a balance between giving the family privacy and letting them know you are there to support them								
**We explain to the family what is happening when their relative is dying e.g. breathing changes and the reason for using any medication						43.2%	54.5%	2.3%
**We feel able to answer the families questions or direct them to somebody more appropriate						53.4%	41.9%	4.7%
We ensure the family are comfortable and have food and drink						64%	34.2%	1.8%
**Staff communicate with relatives to discuss their involvement with care						53.7%	46.3%	–
**We ensure that families understand that their relative is dying and that they are up to date with what is happening						46.5%	53.5%	–
We ensure good teamwork and good communication between all staff including domestics and activity leaders etc. <ul style="list-style-type: none"> ● Good handovers and continual feedback ● Good documentation of care for the last few days of life 						22.8%	74.6%	2.6%

Individual team members including laundry/domestic/kitchen staff are informed and helped to have a role when a resident is dying						48.2%	42.2%	9.6%
Team members always feel included in a resident's dying phase if they want to be						47.7%	50.9%	1.7%
Staff are supported in this unit to talk openly to residents who are dying						38.7%	59.5%	1.8%
We recognize the importance of dying residents with dementia being in the environment that they are familiar with						43.3%	54.5%	1.8%
We organize staffing to ensure that those who 'really know' the resident especially those with dementia are with them in the last days of life						56.6%	41.5%	1.9%
Dying is acknowledged and not denied						49.5%	48.6%	1.9%
We feel able to manage situations where there is some disagreement between key parties involved e.g. staff, GPs, families						17.9%	74.4%	7.7%
We know where to seek help and advice from other experts when it is required						31.6%	64.9%	3.5%
There is a lot of fear in our unit about caring for a resident who is dying						41.4%	56%	2.6%

PLEASE TURN TO 'After Death' – overleaf

[** denotes questions omitted from questionnaire to care assistants]

	This is a feature of care in this unit...			Effects of the ICP Project		
	All/most of the time	Some of the time	Rarely if ever	The ICP project has had no effect on this	The ICP project has helped us do it better	We've only done it since the ICP project began
<p>AFTER DEATH</p> <p>We ensure appropriate respect for the body after death</p> <ul style="list-style-type: none"> ● Last offices ● Removal of the body from the nursing home 				60%	39.2%	0.8%
There is agreement in our home about what happens to the resident's body after death				65.5%	32.7%	1.8%
Staff have an understanding about the grieving process and the importance of families paying their last respects after a resident has died.				48.2%	50.9%	0.9%
We offer an opportunity to share with relatives details of what happened in the final hours if the family were absent.				62.2%	35.6%	2.2%
**We check that the family have the information they need about what to do after a death				60%	40%	–
**Other residents who knew the person well are informed that the person is dying/has died				58%	40.2%	1.8%
All staff are informed when a resident has died				68.2%	30.9%	0.9%
Staff are supported when a resident dies				60.6%	39.4%	–
We offer assistance to the family to carry out practical arrangements i.e. clear the room after a resident has died				70.3%	28.8%	0.9%

Staff have the opportunity to pay their respects to the family/resident by going to the funeral and/or having time to say goodbye						71.3%	28.7%	–
There is a forum for open discussion/reflection after a death to support staff and further development in care of the dying						34.2%	55.6%	10.2%

THANK YOU VERY MUCH INDEED FOR COMPLETING THIS – IT WILL BE VERY HELPFUL

[** denotes questions omitted from questionnaire to care assistants]

APPENDIX 15

AN INTEGRATED CARE PATHWAY FOR THE LAST DAYS OF LIFE

(an adapted version of the Liverpool Care Pathway¹)

(‘NURSING HOMES’)

AIMS:

- *to continue to provide person-centred/holistic care & support to the dying resident – bringing physical, mental, emotional & spiritual comfort*
- *to provide support and care to the relatives/friends of the dying resident*
- *to provide instruction/support to staff so that they feel confident in the care of dying residents helping staff to enhance a kind, thoughtful, and professional attitude to death*

A Care Pathway is intended as a guide to treatment and an aid to documenting a person’s care progress. Clinicians are free to exercise their own professional judgements as appropriate. Any alteration to the practice identified within this ICP should be noted as a ‘variance’ on the sheet towards the back of the pathway.

For further information please contact:

**Jo Hockley (Research Fellow/CNS) or Julie Watson (Research Assistant)
St Columba’s Hospice**

**Tel: 0131 551 1381 x 168
email: jo@stcolumbashospice.org.uk**

¹ © LCP Project Team at the Marie Curie Palliative Care Institute, Liverpool.

INTEGRATED CARE PATHWAY FOR A DYING PERSON

This integrated pathway provides a structured approach to providing care for a resident in their last days or hours of life. The pathway integrates the essential assessments with guidelines for potential problems and a multidisciplinary communication process. Although the pathway provides structure to the process of care, it should not replace clinical decision-making and judgement – particularly in complex cases. The pathway is split into 5 sections as follows:

Section 1: Resident/family initial assessment (white)

- | | |
|--------------------------|----------------------|
| c) comfort measures | c) spiritual support |
| d) psychological insight | d) communication |

Section 2: Resident/family ongoing problems/focus

- | | |
|--|---|
| <i>4hrly assessments of:</i> (Pale yellow) | <i>12hrly assessments on:</i> (Dark yellow) |
| c) pain/symptom control | a) bowel care |
| d) treatment/procedures | b) psychological insight/support |
| c) mobility/pressure area care | c) spiritual care |
| d) medication | d) care of family/others |

Section 3: Interdisciplinary communication

Good communication is essential to good palliative care. The ICP and multidisciplinary notes sheet should be used by all staff.

Section 4: Variance reporting

Variance reporting is central to the philosophy of the integrated pathway. If a 'goal' is not achieved (variance) then a variance needs to be recorded in this variance section. Persistent variances (such as distress) should prompt the staff to refer to the guidelines (detailed in the next section).

Section 5: Guidelines

Guidelines give clear instructions (based on evidence & clinical experience of specialist) on how to address specific problems. The guidelines cover:

- Symptom management including pain; use of fentanyl patches, syringe drivers etc
- Obtaining palliative care medications out of hours;
- The Final Act of Care – 'last offices'
- Bereavement booklet/leaflet
- Sharing difficult information including giving information by telephone
- How to contact specialist palliative care services

Instructions for use:-

5. The ICP is intended as a single record that replaces all other notes/care plans and is used by all staff.
6. All goals are in bold type. Prompts to help staff assess whether goals have been met are in normal type.
7. If a goal is not achieved (ie a variance occurs) then record this in the variance section (page 12).
8. The palliative care guidelines for the pathway are included at the end of the document.
Specialist palliative care advice is available by telephone 24 hours a day, 7 days a week by contacting St Columba's Hospice or Marie Curie Centre Fairmile

NAME.....

ROOM NUMBER.....

DATE.....//.....

SECTION 1		INITIAL RESIDENT ASSESSMENT	
PHYSICAL CONDITION	GENERAL ASSESSMENT of current physical problems		
	<i>(If 'YES' to any of the problems in this small section, refer to the guidelines at back of ICP)</i>		
	Unable to swallow	Yes <input type="checkbox"/> No <input type="checkbox"/>	see guideline (s/c infusion compatibility)
	Nausea/vomiting	Yes <input type="checkbox"/> No <input type="checkbox"/>	see guideline 4 (nausea & vomiting)
	Confused	Yes <input type="checkbox"/> No <input type="checkbox"/>	see guideline 2 (management of confusion)
	Agitation/restless	Yes <input type="checkbox"/> No <input type="checkbox"/>	see guideline 2 (management of agitation)
	Anxiety/fear	Yes <input type="checkbox"/> No <input type="checkbox"/>	see guideline 2 (management of anxiety)
	Pain	Yes <input type="checkbox"/> No <input type="checkbox"/>	see guideline 1 (management of pain)
	Breathlessness	Yes <input type="checkbox"/> No <input type="checkbox"/>	see guideline 3 (breathlessness)
	Respiratory Tract Secretions	Yes <input type="checkbox"/> No <input type="checkbox"/>	see guideline 3 (respiratory tract secretions)
	Constipated	Yes <input type="checkbox"/> No <input type="checkbox"/>	
	Sadness	Yes <input type="checkbox"/> No <input type="checkbox"/>	
COMFORT MEASURES	NB: If you answer 'NO' to any 'goal' please chart as variance (p.12)		
	Goal 1: Current medication assessed and non essentials discontinued: Yes <input type="checkbox"/> No <input type="checkbox"/> Inappropriate medication is discontinued. Any regular oral analgesics or anxiolytics/antidepressants need to be re-prescribed appropriately [subcutaneous and/or syringe driver, transdermal or PR route].		
	Goal 1a: If syringe driver to be used – it has been set up within 4 hrs: Yes <input type="checkbox"/> No <input type="checkbox"/> Time that s/c prescription written/ordered by GP: <input type="text"/>		
	Goal 2: PRN medication [s/c or PR] written up i.e.:		
	s/c diamorphine 1.25-2.5mg prn for pain		None prescribed <input type="checkbox"/>
	s/c hyoscine for respiratory tract secretions		Yes (some drugs) <input type="checkbox"/>
	PR Diazepam 5mg; or s/cMidazolam 2.5-5mgs 1-2hrly; or s/c Methotrimeprazine 12.5mg/6hrly for increasing agitation		Yes (all drugs) <input type="checkbox"/>
	Goal 3a: Discontinue inappropriate interventions:		
	Blood sugars	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	
	Antibiotics	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	
Naso-gastric tube feeding/PEG tube/s.c.fluids	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>		
Goal 3b: Decision to discontinue inappropriate nursing interventions taken: Yes <input type="checkbox"/> No <input type="checkbox"/> i.e. Taking TPR/BP monitoring			
Goal 3c: Resident has 'comfort' equipment as necessary: Yes <input type="checkbox"/> No <input type="checkbox"/> i.e. suitable mattress; fan			
<i>If you have charted "No" against any goal, please complete <u>variance sheet</u> (pg 12)</i>			
Nurse signature Date Time			
GP signature..... Date Time			

NAME.....

ROOM NUMBER.....

DATE.....//.....

SECTION 1 INITIAL RESIDENT ASSESSMENT (Contd/...)																	
PSYCHOLOGICAL/ INSIGHT	<p>Goal 4: Ability to communicate in English assessed as adequate: Yes <input type="checkbox"/> No <input type="checkbox"/></p> <ul style="list-style-type: none"> Relevant when resident/family are from ethnic minority group 																
	<p>Goal 5a: Encouraging 'open' communication about dying– even with cognitive impairment, it is possible sometimes for a nurse/carer to know if the resident is aware they are dying. Be prepared to ask: Is there anything worrying or frightening you?</p> <table border="0"> <tr> <td></td> <td style="text-align: center;">Unconscious</td> <td style="text-align: center;">Yes</td> <td style="text-align: center;">No</td> </tr> <tr> <td>Is there recognition of dying?</td> <td>a) Resident <input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td></td> <td>b) Family <input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td></td> <td>c) Other (please specify): <input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>		Unconscious	Yes	No	Is there recognition of dying?	a) Resident <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		b) Family <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		c) Other (please specify): <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		Unconscious	Yes	No													
Is there recognition of dying?	a) Resident <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>														
	b) Family <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>														
	c) Other (please specify): <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>														
<p>Goal 5b: Dealing with any 'unfinished business' – after someone dies any 'issues' a family member/s might have can never be resolved. Sometimes it is helpful for staff to facilitate an opportunity to discuss unresolved issues. Has this been assessed? Yes <input type="checkbox"/> No <input type="checkbox"/></p>																	
RELIGIOUS/ SPIRITUAL SUPPORT	<p>Goal 6: Assessing religious/spiritual needs. A resident/family may not ask for prayers to be said/minister to visit etc. but often respond very positively when asked-especially if resident has had church involvement previously. Consider other spiritual needs as appropriate</p> <p>Have religious/spiritual needs been assessed with resident/family? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Formal religion:Minister of religion (name)</p> <p>Telephone No:</p> <p>Please record particular needs now, at time of & after death (ceremonial washing, cremation, burial etc) :</p>																
COMMUNICATION WITH FAMILY/OTHER	<p>Goal 7: Family/other have been informed of resident's impending death: Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>When being informed, do the family/friend want to be contacted when resident deteriorates further/dies:</p> <p>At any time <input type="checkbox"/> Not at night-time <input type="checkbox"/> Staying overnight somewhere: <input type="checkbox"/> (please specify)</p> <p>1st Contact (Name + relationship to resident)</p> <p>Tel no: Mobile</p> <p>2nd contact</p> <p>Tel no: Mobile</p>																
	<p>Goal 8: Family/other know they can telephone/visit at any time: Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Have family got somewhere locally to stay? Are they taking regular food/refreshment? Do they know where washrooms/toilets are?</p>																
COMMUNICATION WITHIN PRIMARY CARE TEAM	<p>Goal 9:</p> <p>GP has informed 'out of hours' service that resident is dying: Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>'Hand-over sheet' faxed to local 'out of hours co-op': Yes <input type="checkbox"/> No <input type="checkbox"/></p>																
SUMMARY	<p>Goal 10: Plan of care discussed. Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Discussed with: a) Resident <input type="checkbox"/> b) Family <input type="checkbox"/> c) Representative: <input type="checkbox"/> (please specify)</p>																
	<p>Goal 11: Family/other express understanding of plan of care: Yes <input type="checkbox"/> No <input type="checkbox"/></p>																
<p><i>If you have charted "No" against any goal, please complete <u>variance sheet</u> (pg 12) before signing below: If further space needed for any goal please record on 'inter-disciplinary sheet' (pg 9)</i></p> <p>Nurse signature.....Date.....Time.....</p> <p>GP signature.....Date.....Time.....</p>																	

NAME.....

ROOM NUMBER.....

DATE.....//.....

SECTION 2: RESIDENT PROBLEMS/ISSUES
--

*Codes (Please enter in columns) <u>A = Achieved</u> <u>V = Variance**</u> (See pg. 12 for recording of 'variance')**		02.00	06.00	10.00	14.00	18.00	22.00
		A	V	V	A	A	A
ASSESSMENT PAIN/COMFORT MEASURES							
Goal 22: Resident is PAIN FREE: <ul style="list-style-type: none"> • if awake, is the resident in pain when asked? • if unconscious, is resident 'pain free' on movement? 							
Goal 23: Resident is PEACEFUL: i.e. not agitated nor restless nor fearful <ul style="list-style-type: none"> • Is the resident showing signs of delirium i.e. trying to get out of bed/plucking at bedclothes? • Is the resident twitching? If so, make sure they are not having too much morphine/pain killers • Is the resident mildly restless? If so, exclude full bladder +/- constipation • Does the resident appear fearful so they can't fall asleep? 							
Goal 24: Resident's BREATHING is calm and not noisy: <ul style="list-style-type: none"> • Is the rate of respirations very rapid? • Does the breathing sound wet/bubbly? 							
Goal 25: Resident is NOT NAUSEAOUS/VOMITING: <ul style="list-style-type: none"> • Is the resident feeling/being sick? 							
Goal 26: Other assessments as appropriate: Pulse will become slow and thready when dying more imminent – please record 'T' = thready when this is noted							
TREATMENT/PROCEDURES							
Goal 27: Mouth is clean All mouth care given and/or fluids/sucking from sponge or gauze as able. Note by * if still drinking + detail amount. Mark as variance if mouth dirty and/or thrush present.							
Goal 28: Resident has passed urine &/or is comfortable Please indicate by* if urine passed within last 4hrs. Only mark as 'variance' if resident is restless due to full bladder – indicating the need of a urinary catheter.							
Goal 29: Resident is comfortable/no sore developing Pressure area care attended + use of special mattress. Change position as appropriate. Full wash given – [please indicate by *]. Note peripheral shutdown (blotchy blue skin) here or on Pg 9/10. Use Goal 37 if pressure sore present or daily dressing needed.							
Goal 30: Resident's safety is ensured Use of cot sides if appropriate							
<u>CARERS/NURSES INITIALS:</u>	/	/	/	/	/	/	/

NAME.....

ROOM NUMBER.....

DATE...../.../.....

SECTION 2 (Contd/....) RESIDENTS PROBLEMS/ISSUES
Trained nurse responsibility to complete

*Codes (Please enter in columns) <u>A = Achieved</u> <u>V = Variance**</u>		** See pg.12 for recording of variance		02.00 (night shift) A		14.00 (day shift) V	
MEDICATION	Goal 31: All medication is given safely & accurately as per drug kardex * If syringe driver in progress – charted & CHECKED on appropriate chart every 6hrs * If medication not required record as N/A	02.00	06.00	10.00	14.00	18.00	22.00
				06.00 (night shift)		14.00 (day shift)	
BOWEL CARE	Goal 32: Resident is not agitated/distressed by bowels Both constipation & 'overflow' can be a problem in the last days of life - either can be very distressing. If this is a problem then they generally need a gentle examination followed by Bisacodyl supps. Mark * if bowels opened during shift						
INSIGHT/ PSYCHO- LOGICAL SUPPORT FOR RESIDENT AND FAMILY	Goal 33: Resident becomes aware of situation as appropriate. It can be frightening to suddenly be moved – keep resident informed of what you are doing. Resident may tell you that he is seeing people who have already died. Note this down in this box or Pg 9/10. Support the resident by 'being with' them especially if there is no family present – detail this by * + length of time spent sitting.						
	Goal 34: Family/representative express understanding of plan of care. <ul style="list-style-type: none"> Regularly check amount of involvement in care family desire Check understanding through stages of dying: possibility of physical symptoms e.g 'rattly' chest, cold/hands & feet, mottling of skin, irregular breathing (cheyne stokes breathing) Record here or pg 9 as appropriate. If family have not visited & no telephone contact during shift put N/P						
RELIGIOUS / SPIRITUAL SUPPORT	Goal 35: Appropriate religious/spiritual support given. Detail aspect of spiritual support being given: i.e. visit by priest, music playing, religious text read, poetry etc. [detail in box as appropriate]						
CARE OF THE FAMILY / OTHERS	Goal 36: The needs of those attending the resident are met Information shared freely with family/friends during shift and refreshments offered– family need regular breaks/refreshment. [If family/friend 'not present' for shift put N/P]						
DRESSINGS	Goal 37: Any dressings have been attended to appropriately Please state procedure below– if none detail in box as N/A						
IF YOU HAVE CHARTED 'V' AGAINST ANY GOAL, PLEASE COMPLETE VARIANCE SHEET (Pg 12) BEFORE SIGNING Repeat these pages 24 hrly. Spare copies in staff office***				Nurse Initial:		Nurse Initial:	

ICP - VERIFICATION OF DEATH + ADMINISTRATIVE PROCEDURE

NAME:..... **DOB:** **DATE:**

Date of Death **Time of Death**

Persons Present

Signature **Time death certified by GP.**

Goal 12a: GP practice contacted re death	Date: ___/___/___	Yes <input type="checkbox"/> No <input type="checkbox"/>
12b: Family/representative informed if not present	Date: ___/___/___	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
12c: Other residents informed	Date: ___/___/___	Yes <input type="checkbox"/> No <input type="checkbox"/>
12d: Other services informed (i.e. social worker)	Date: ___/___/___	Yes <input type="checkbox"/> No <input type="checkbox"/>
12e: Inform Head Office, as appropriate		Yes <input type="checkbox"/> No <input type="checkbox"/>
Goal 13a: Procedures for 'final act of care' according to Nursing Home		Yes <input type="checkbox"/> No <input type="checkbox"/>
13b: Removal of body from nursing home carried out according to 'policy'		Yes <input type="checkbox"/> No <input type="checkbox"/>
Goal 14: Alternative procedure following death discussed or carried out (If 'yes' please indicate)		N/A <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>
Resident had infectious disease	<input type="checkbox"/>	Procurator fiscal notified <input type="checkbox"/>
Post mortem discussed	<input type="checkbox"/>	
Goal 15: NH policy followed for resident's valuables & belongings		Yes <input type="checkbox"/> No <input type="checkbox"/>
<ul style="list-style-type: none"> • Belongings listed and resident's room tidied + room to be locked. • Valuables listed and put in safe. Returned to family and a signed receipt given 		
Goal 16: Family/other given information on what they need to do		Yes <input type="checkbox"/> No <input type="checkbox"/>
<ul style="list-style-type: none"> • Collect death certificate from NH/GP surgery/registrar • To contact registrars office to arrange a time to register death • To contact funeral directors to arrange funeral [Name of funeral director:] • If resident is to be cremated, a cremation form is signed by 2 doctors and sent to undertaker 		
Goal 17: Necessary documentation + advice is given as appropriate		Yes <input type="checkbox"/> No <input type="checkbox"/>
<ul style="list-style-type: none"> • Pension book returned to DSS or given to family • Notification of death form to be completed and sent to care commission • Death entered into Residents Register 		
Goal 18: Bereavement leaflet/book given to relative/close friend		Yes <input type="checkbox"/> No <input type="checkbox"/>
<ul style="list-style-type: none"> • Explain re 'how to register death' + likely reaction to grief as in booklet 		
Goal 19: Care Commission advised of death		Yes <input type="checkbox"/> No <input type="checkbox"/>
Goal 20: ICP returned to resident's notes – now deceased		Yes <input type="checkbox"/> No <input type="checkbox"/>
<ul style="list-style-type: none"> • Case notes kept for a minimum of 3 years from date of death 		
IF YOU HAVE CHARTED "NO" AGAINST ANY GOAL SO FAR, PLEASE COMPLETE VARIANCE SHEET (page 12) BEFORE SIGNING BELOW		
Nurse Signature Date		
**HAVE YOU COMPLETED THE LAST 4 & 12 HOURLY OBSERVATION		

