LCP CENTRAL TEAM UK
MCPCIL

Liverpool Care Pathway for the Dying Patient (LCP)

Goal Definitions / Data Dictionary Version 11 LCP

July 2008

Adapted for use in NZ with addition of goals 6b & 18b - December 2008

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Introduction

The Liverpool Care Pathway for the Dying Patient (LCP) was developed in the U.K to transfer the hospice model of care into other care settings. It is a multi-professional document that provides an evidence-based framework for end of life care.

The LCP provides guidance on the different aspects of care required, including comfort measures, anticipatory prescribing of medicines and discontinuation of inappropriate interventions. Additional psychological, spiritual and cultural care and family support are included.

The LCP replaces all other documentation in this phase of care and is applicable in hospital, hospice, rest home and community settings A key feature of the LCP is that it empowers generic health care workers to deliver quality, evidence-based end-of-life care.

Ownership by local healthcare services of the framework is imperative for implementation and sustainability of the LCP within the clinical arena. However, those services registered with LCP Central (UK) who want to be part of wider evidence and research programmes and be involved in future benchmarking and National Audit activity will need to keep the core goals exactly as outlined within the document.

Nevertheless, the prompts which support the goals can be adapted to better reflect local practice, provided that they do not alter the meaning of the stated goal.

It is important that generic health workers have access to appropriate specialist palliative care advice and support.

Instructions for use:

1. All 'goals of care' (outcomes) in the LCP are in **bold** typeface. Below some goals are 'prompts' which inform the rationale of the goal.
2. If you tick 'NO' for any goal this is a variance. The reason for the variance from the recommended best practice is then recorded on the variance page. A variance is not a failure. Analysis of variances "provide a mechanism for analyzing the reasons for not achieving the desired outcomes of care" (Ellershaw & Wilkinson, 2003, p.12).
3. Guidelines for the safe administration of appropriate medications for the management of the five main end-of-life symptoms - pain, agitation, nausea and vomiting, respiratory tract secretion and dyspnoea – are attached to the end of every LCP.

If you require further information or support please contact your Specialist Palliative Care Service

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GOAL 1 CURRENT MEDICATION ASSESSED AND NON ESSENTIALS DISCONTINUED

RATIONALE

- To avoid unnecessary distress of continuing with medication which may be futile when no clear benefit can be gained.
- To consider an alternative route of administration.

REQUIRED BEHAVIOUR

MDT discussion to:
Stop, Think, Assess, and Change your practice accordingly

- Review medication and discuss the purpose of all medications on commencement of the LCP.
- Discontinue any inappropriate medication.
- Convert any appropriate medication to subcutaneous route.
- Consider the need for a continuous subcutaneous infusion of medication (via a syringe driver).

CODING

- Code **YES** when all *appropriate* measures have been carried out
- Code **NO** when one or more *appropriate* measures has not been carried out

GOAL 2 PRN SUBCUTANEOUS MEDICATION WRITTEN UP FROM LIST BELOW AS PER PROTOCOL (2.1 - 2.5)

RATIONALE

- These 5 key symptoms have been recognised as actual or potential symptoms at the end of life.
- Anticipatory prescribing will ensure minimal delay responding to a symptom if or when they arise.

REQUIRED BEHAVIOUR

Refer to the algorithms at the end of the LCP to underpin prescribing (appropriate medications/dose etc) according to local policy and procedure.
Anticipatory Prescribing of appropriate PRN medication for all 5 symptoms (whether or not the patient is displaying these symptoms on commencement of pathway).

CODING

- Code **YES** when each of the appropriate medications has been written up according to protocol.
- Code **NO** against any drugs that have not been written up or not written up as per protocol

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GOAL 3 DISCONTINUE INAPPROPRIATE INTERVENTIONS
3.1 BLOOD TESTS
3.2 ANTIBIOTICS
3.3 IV FLUIDS AND/OR MEDICATION

RATIONALE

To avoid invasive, futile, potentially painful and unnecessary procedures/ interventions being carried out when no clear benefit can be gained.

REQUIRED BEHAVIOUR

Stop, Think, Assess, and Change your practice accordingly
Practitioners are free to exercise their own professional judgement; however any alteration to the practice identified within the LCP must be noted as a variance

- Discontinue **routine** blood tests
- Discontinue the use of antibiotics
- Discontinue IV fluids/medications.

CODING

- Code **YES** against each intervention when it has been discontinued
- Code **NO** against any intervention that has not been discontinued
- Code **N/A** when an intervention was not being carried out.

GOAL 3.4 NOT FOR CARDIOPULMONARY RESUSCITATION (CPR) RECORDED

RATIONALE

To avoid invasive, futile, potentially painful and unnecessary procedures/ interventions being carried out when no clear benefit can be gained.

REQUIRED BEHAVIOUR

Stop, Think, Assess, and Change your practice accordingly

- Follow local policy/procedure
- Complete appropriate associated documentation
- Record also directly on LCP
- Discuss and inform patient & or family/whanau/other as appropriate.

CODING

- Code **YES** when a 'not for CPR' decision has been made and appropriately documented according to policy/procedure.
- Code **NO** when a decision has not been made and/or has not been appropriately documented according to policy/procedure.

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GOAL 3.5 DEACTIVATE IMPLANTED CARDIAC DEFIBRILLATORS (ICD'S)

RATIONALE

Continuing cardiac defibrillation until the point of death can be distressing and confusing to the family/whanau/other when no clear benefit can be gained.

REQUIRED BEHAVIOUR

Stop, Think, Assess, and Change your practice accordingly

- Refer to and follow local policy and procedures for deactivation
- Contact the patients cardiologist
- Give information leaflet to patient/family/whanau/other wherever appropriate in support of best practice

CODING

- Code **YES** when appropriate policy and procedure has been carried out and cardiac defibrillator has been deactivated

- Code **NO** when the cardiac defibrillator has not been deactivated

- Code **N/A** when the patient did not have a cardiac defibrillator fitted

GOAL 3a DECISIONS TO DISCONTINUE INAPPROPRIATE NURSING INTERVENTIONS TAKEN

RATIONALE

To ensure that nursing interventions are appropriate for a specific individual – some interventions will no longer be appropriate for this period of care.

REQUIRED BEHAVIOUR

Stop, Think, Assess, and Change your practice accordingly

- Stop taking **routine** vital signs
- Reduce frequency of or discontinue BM monitoring
- Change from **routine** turning regimes to a regime aimed at repositioning for comfort only.

CODING

- Code **YES** if all the above have been carried out (wherever appropriate).

- Code **NO** if one or more of the above have not been carried out (wherever appropriate)

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GOAL 3b SYRINGE DRIVER SET UP WITHIN 4 HOURS OF DOCTOR'S ORDERS

RATIONALE

To ensure that the equipment supporting continuous subcutaneous infusion of medication in support of symptom management is available as and when required.

REQUIRED BEHAVIOUR

Stop, Think, Assess, and Change your practice accordingly

- If required obtain a syringe driver & use according to local policy and procedure.
- If not available be able to manage symptoms with regular subcutaneous injections.

CODING

- Code **ALREADY IN PLACE** if the syringe driver was already in use prior to the initiation of the LCP
- Code **YES** if a syringe driver was requested and was set up within 4 hours of Dr's order
- Code **NO** when a syringe driver was required but not set up (at all or within 4 hours).
- Code **N/A** if syringe driver not required on commencement of the LCP

GOAL 4 ABILITY TO COMMUNICATE IN ENGLISH ASSESSED AS ADEQUATE WITH PATIENT AND CARER

4a) PATIENT
4b) FAMILY/WHANAU/OTHER

RATIONALE

- To support communication /psychological/insight into care management.
- Some patients and/or carers or members of family/whanau/other may not use English as their first language.
- Some patients and or family/whanau/other may have learning difficulties.

REQUIRED BEHAVIOUR

Consider the first language of your patient and family/whanau/other. If this is not English you may need to consider the use of an interpreting service.
If for any other reason your patient, family/whanau/other cannot fully understand English due to any other reason, e.g. learning difficulties, hearing impairment then you may need to seek support in your communication processes.

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CODING

- Code **YES** when no support is needed to facilitate appropriate communication with (a) patient and/or (b)family/whanau/other.

- Code **NO** when you have identified the need for support to facilitate appropriate communication with (a) patient and/or (b) family/whanau/other.

GOAL 5 INSIGHT INTO CONDITION IS ASSESSED
(5a & 5b) AWARE OF DIAGNOSIS
(5c & 5d) RECOGNITION OF DYING

RATIONALE

- To ensure, where appropriate, that the patient & or family/whanau/other are aware of the patient's diagnosis and that the patient is now thought to be in the dying phase

- To ensure that you as a health professional are aware of the knowledge status in support of future conversations you may have – particularly at the bedside – so as to maintain appropriate confidentially and respect.

REQUIRED BEHAVIOUR

Patient

- Remember this goal refers to your understanding of the knowledge level of your patient
- If you have prior knowledge that the patient has expressed an awareness then it may not be necessary to have a further conversation at this time if you feel that this is inappropriate.
- If a conversation is deemed appropriate at this time, remember, it can be a difficult conversation to have. You need to recognize your limitations and seek advice and support where appropriate.

Family/Whanau

- Ascertain by using prior knowledge or current discussion the knowledge base of the family/whanau/other and code accordingly.

CODING

Patient

- Code **YES** if you know that the patient is aware, either due to your prior knowledge or because you have explained this to the patient at this moment in time.

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- Code **NO** if you know that the patient is not aware or if you are unsure of their level of knowledge but despite having the opportunity you do not attempt to assess the patient's insight, for example:
  - Patient requested never to hear bad news.
  - Patient is alone and you want to have this conversation when family/ whanau/other present.
  - Patient is not well enough in your professional opinion to have this discussion despite being conscious.
  - You do not feel able to address this issue at this time.

- Code **Comatosed** if you know that the patient is not aware or if you are unsure of their level of knowledge but you do **NOT** have an opportunity to have a conversation because the patient is comatosed at this time.

Family/Whanau/Other

- Code **YES** if you know that the family/whanau/other is aware, either due to your prior knowledge or because you have explained this to the family/whanau/other at this moment in time.

- Code **NO** if you know that the family/whanau/other is not aware or if you are unsure of their level of knowledge but despite having the opportunity you do not attempt to assess the patient's insight. For example:
  - Patient requested that you do not discuss their care with family/whanau/other
  - The family/whanau/other are not present at the time of the assessment and you need to address this at a later date
  - You do not feel able to address this issue at this time

GOAL 6A RELIGIOUS/SPIRITUAL NEEDS ASSESSED
6Aa) PATIENT
6Ab) FAMILY/ WHANAU/ OTHER

RATIONALE

- To ensure that any religious or spiritual need is highlighted and addressed if required now, at impending death or after death.

REQUIRED BEHAVIOUR

a) Patient

- Because the focus of care has now changed to care of the dying, even if it is known that the patient has previously been asked about their religious or spiritual beliefs and may indeed have a documented formal religious tradition or spiritual belief on admission a conversation to identify the patient's present spiritual/ religious needs must occur.

- The identified spiritual/religious needs must be documented appropriately.

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b) Family/Whanau/Other

- Irrespective of any prior knowledge or conversations at this moment in time you need to have a conversation with family/whanau/other re
  - The patient's beliefs and wishes if appropriate
  - The family/whanau/other concerns or beliefs

CODING

Patient

- Code **YES** if you had a conversation with the patient and any religious/ spiritual needs (or their absence) have been identified and documented appropriately.

- Code **NO** if you did not have the conversation

- Code **COMATOSED** if it was impossible to have the conversation because your patient is comatosed at this time.

Family/Whanau/Other

- Code **YES** if you had a conversation with the family/whanau/other and any religious/spiritual needs (or their absence) for the patient and the family/ whanau/other were identified and documented appropriately.

- Code **NO** if you did not have the conversation about either (or both) the patient or family/whanau/other spiritual/religious needs.

GOAL 6B CULTURAL NEEDS/SUPPORT REQUIREMENTS ASSESSED WITH PATIENT AND FAMILY/WHANAU/OTHER

RATIONALE

- To ensure that specific cultural needs and traditions are identified and reasonable effort is made to support cultural practices.

REQUIRED BEHAVIOUR

- Irrespective of prior knowledge you need to have a conversation to identify cultural practices/traditions/wishes and needs of the patient and family/whanau/other at this present time.
- Document appropriately, presence or absence of cultural needs/ practices/ traditions/special wishes.

CODING

- Code **YES** if you had a conversation with the patient, family/whanau/other and any cultural needs were identified (or not), and document accordingly.

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- Code **NO** if you did not have this conversation

- Code **COMATOSED** if it was impossible to have this conversation with the patient because they were comatosed at the time.

GOAL 7 IDENTIFY HOW THE FAMILY / WHANAU / OTHER ARE TO BE INFORMED OF THE PATIENTS IMPENDING DEATH

RATIONALE

- It is important when communicating information of a sensitive nature around patients deteriorating condition/impending death that the appropriate person is contacted at an appropriate time.
- Information that was accurate at any other time in this episode of care may not be accurate now that the focus of care has changed to care of the dying.
- Some carers may be working, elderly, or indeed not want to be contacted until the following day irrespective of the patients condition.
- Establishing how family/whanau/other wish to be told of patients impending death is also very important.
- In some situations the next of kin may not be the most appropriate person to be contacted at the time of impending death or a list of people may be given or mobile numbers may be needed.

REQUIRED BEHAVIOUR

- Irrespective of prior knowledge or documentation the health professional must revisit this issue and have a conversation to ensure that the patient's, where appropriate, and the family /whanau/others wishes are known.
- Contact details should be reviewed to ensure the correct details are recorded.

CODING

- Code **YES** if you have had a conversation with the patient and/or family/whanau/other and you have identified and documented
  - A primary and secondary contact
  - Appropriate times/circumstances in which they should be notified.

- Code **NO** if you have not had this conversation

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GOAL 8 FAMILY / WHANAU / OTHER GIVEN INFORMATION

RATIONALE

It is important that written information is given to back up a conversation to ensure that family/whanau/other are aware of facilities available to them at this time, particularly since a more flexible approach to visiting is now likely to be appropriate.

REQUIRED BEHAVIOUR

A specific information leaflet should be given to family/whanau/other

CODING

- Code **YES** if you given the available written documentation/information.
- Code **NO** if you have not provided written documentation/information and document on variance sheet. e.g. If you did not provide written information/ leaflets or family/whanau/other were not available at that point.

GOAL 9 GP PRACTICE IS AWARE OF PATIENTS CONDITION

RATIONALE

- The primary health care team are the primary team managing this patient and should always be kept informed of patient's condition.
- They need to know that the focus of care has changed and an LCP is in progress because
  - Other members of the family may be known to the practice
  - The GP or other member of the primary healthcare team may want to visit the patient or family.

REQUIRED BEHAVIOUR

- If the health professional has knowledge that the GP practice are aware that the patient has entered the dying phase (eg if the patient was referred from primary care for terminal care) there is no need to have further contact with the GP practice at this stage.
- Otherwise, the health professional needs to contact the GP Practice to make them aware of the current situation.

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CODING

- Code **YES** if you know that the GP practice is already aware or you have made contact with the practice (e.g. telephoned, faxed to a safe fax facility)

- Code **NO** If you know that the GP practice is not aware or you are unsure of their level of knowledge and you have not made contact with the practice (e.g. out of hours).

GOAL 10 PLAN OF CARE EXPLAINED AND DISCUSSED WITH PATIENT AND FAMILY/ WHANAU /OTHER
10a) PATIENT
10b) FAMILY / WHANAU / OTHER

RATIONALE

It is important to ensure that the patient and family/whanau/other understand fully the aims of the new plan of care.

REQUIRED BEHAVIOUR

- A discussion must take place between the health professional and the patient (where possible and appropriate) and/or the family/whanau/other to inform them in jargon free language that the focus of care has now changed to care of the dying
- It is at this time that health professionals may introduce the Coping with Dying leaflet in support of their conversation that outlines what signs and symptoms may be expected in the last hours/days of life, if deemed appropriate.
- Similarly, the family/whanau/other may also benefit at this time from the LCP information leaflet. However, these leaflets should only be used to support the conversations undertaken.

CODING

10a) Patient

- Code **YES** if you have had a conversation in which you have explained the revised plan of care to the patient.

- Code **NO** if despite having an opportunity you did not have a conversation with the patient to explain the plan of care

- Code **COMATOSED** if you did **NOT** have an opportunity to have a conversation because the patient was comatosed at this time.

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10b) Family/Whanau/Other

- Code **YES** if you had a conversation in which you explained the revised plan of care to the family/whanau/other.

- Code **NO** if despite having an opportunity you did not have a conversation with the family/whanau/other to explain the plan of care.

GOAL 11 FAMILY / WHANAU / OTHER EXPRESS UNDERSTANDING OF PLANNED CARE

RATIONALE

- It is important to ensure and to check that our communications have been fully understood.
- To give an opportunity to the family/whanau/other to verbalise that they have understood that:
  - The focus of care has changed to care of the dying
  - A specific plan of care has been activated in support of the key goals of care for the last hours or days of life and their concerns are identified, valued and documented.

REQUIRED BEHAVIOUR

A conversation must take place between the health professional and the family/ whanau/other to:

- Enable the family/whanau/other to verbalise their understanding of the current situation.
- Give them an opportunity to express their concerns and recognize that these are valued and documented.

CODING

- Code **YES** if you have had the conversation during which the family/whanau/other clearly articulated their understanding of the situation.

- Code **NO** if despite having an opportunity you did not have a conversation with the family/whanau/other **OR** if you had the conversation but the family/whanau/other did not articulate a clear understanding of the situation.

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GOAL 12 GP PRACTICE CONTACTED RE PATIENTS DEATH

RATIONALE

To improve communication between primary and secondary care the GP practice must be informed of the patients death so that

- The GP can cancel any outstanding appointments for that patient.
- The GP can then support any family/whanau members who may be known to that practice.

REQUIRED BEHAVIOUR

The Health Professional must either:

- Speak to the GP directly
- Leave a message with the receptionist
- Fax the information to a safe fax facility

If the patient dies out of hours and you are unable to contact the GP practice, they must be contacted at the next available opportunity.

CODING

- Code **YES** if you have contacted the GP or left a message with the receptionist.

- Code **NO** if you have not contacted the GP directly, left a message with the receptionist or received confirmation (electronic or otherwise) that a fax has been received by the GP Practice.

GOAL 13 PROCEDURES FOR LAYOUT OUT FOLLOWED ACCORDING TO POLICY

RATIONALE

- It is important to ensure that the body is treated with dignityand respect and appropriately in line with any appropriate rituals for followers of particular faiths/beliefs.
- Each facility will have their own policy for laying out patient's, consult your own local policy
- All specific religious/spiritual/cultural needs should be considered at this time.

REQUIRED BEHAVIOUR

- Local policy re laying out must be followed.
- Any religious/spiritual/cultural needs of the patient/family/whanau must be respected

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CODING

- Code **YES** if you have followed hospital policy re laying out and you have adhered to the religious/spiritual/cultural needs of the patient/family/whanau.

- Code **NO** if you did not follow local policy or did not adhere to the religious/ spiritual/cultural needs of the patient.

GOAL 14 PROCEDURES FOLLOWING DEATH DISCUSSED OR CARRIED OUT

RATIONALE

- When the patient dies **appropriate** procedures need to be considered.
- It is important that you discuss mortuary viewing with the family/whanau/other as there may be family members who were not present at the time of death who may wish to view the deceased.
- If the patient has a cardiac device or pacemaker the family should be aware that this would need removing prior to cremation.
- There are some circumstances that require a Post Mortem to be carried out; these must be discussed with the family/whanau where appropriate.

REQUIRED BEHAVIOUR

Consider each of these procedures and discuss with the family/whanau/other as appropriate.

CODING

- Code **YES** if you have considered the above points and discussed them with the family/whanau/other as appropriate.

- Code **NO** if you did not consider or discuss the above points with the family/whanau at this time. It may be deemed inappropriate to discuss at this time or family/whanau may not have been available at that time.

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GOAL 15 FAMILY/WHANAU/OTHER GIVEN INFORMATION ON PROCEDURES

RATIONALE

At this distressing time retaining information may be difficult. Famiy/whanau/other must be given written information regarding *local* policies & procedures that must be performed after the death.

REQUIRED BEHAVIOUR

Family must be given written information regarding *local* policy and procedures.

CODING

- Code **YES** if you have provided such written information.
- Code **NO** if you did not provide such written information

GOAL 16 HOSPITAL POLICY FOLLOWED FOR PATIENTS VALUABLES & BELONGINGS

RATIONALE

Sometimes seemingly insignificant items belonging to the deceased patient can hold special memories for the family/whanau/others. It is, therefore important that all items belonging to the patient are collected and stored appropriately until the family/whanau are able to collect them.

REQUIRED BEHAVIOUR

- When a patient dies their valuables and belongings must be listed, packed and stored according to local policy
- Family/whanau/other must be informed of how belongings and valuables can be collected

CODING

- Code **YES** if you followed local policy.
- Code **NO** if you did not follow local policy

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GOAL 17 NECESSARY DOCUMENTATION & ADVICE IS GIVEN TO THE APPROPRIATE PERSON

RATIONALE

This can be a distressing time for families and retaining verbal information may be difficult. Family/whanau must be given written information regarding any legal requirements at the time of death for which they are responsible.

REQUIRED BEHAVIOUR

Ensure family/whanau are provided with written information about their responsibilities. The Department of Internal Affairs "Before Burial or Cremation" booklet provides relevant up to date information of the legal requirements about death in New Zealand.

CODING

- Code **YES** if you provided the booklet "Before Burial or Cremation" and/or other relevant piece of national information.

- Code **NO** if you did not provide the booklet "Before Burial or Cremation" and document as a variance.

Note- "Before Burial or Cremation" booklets can be ordered from The Department of Internal Affairs: Email: bdm.nz@dia.govt.nz Freephone: 0800 22 52 52

GOAL 18a BEREAVEMENT LEAFLET GIVEN

RATIONALE

This can be a distressing time for families/whanau/other and retaining verbal information may be difficult. It is important that they are made aware of bereavement issues, both about the grieving process and how to access help and support locally.

REQUIRED BEHAVIOUR

Ensure family/whanau/other are provided with written information about:

- The grieving process
- How to access help and support locally

CODING

- Code **YES** if you have given written information about the grieving process and how to access help and support locally.
- Code **NO** if you have not given written information about the grieving process and/or how to access help and support locally.

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GOAL 18b ARRANGEMENTS FOR BLESSING OF ROOM / BEDSPACE MADE

RATIONALE

In respect of the tangata whenua culture of Aoteroa, karakia/prayer is offered to bless the room before it is reused.

REQUIRED BEHAVIOUR

Refer to local policy/practice re blessing of the room.

CODING

- Code **YES** if arrangements have been made to bless the room.
- Code **NO** if you are unable to bless the room.

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VARIANCE REPORTING

- Variance tells the true story of the patient journey.
- If you have coded a **NO** against any goal this must be recorded as a variance on the Variance Sheet. Variance is not negative but may highlight an appropriate clinical professional judgement for a moment in time that promotes individualized patient care.
- A variance should be documented to include:
  - What variance occurred & why?
  - The action taken by the healthcare professional at this time
- Variance recording also allows an opportunity for the healthcare professional to make an intervention and record an outcome accordingly.

VARIANCE REPORTING

In the ongoing assessment section it is the condition of the patient that is assessed (i.e. whether the patient is comfortable against a series of indices).

It is suggested that the patient should be assessed four hourly or twelve hourly at the times indicated on the document as a **minimum standard** of care for inpatient units and at each visit in the patient's own home. This reflects the patient's condition for that moment in time only.

If you assess the patient more regularly than the stated four or twelve hourly minimum and you find that the patient is not comfortable against any of the indices, you should record your finding directly on to the variance sheet, along with an explanation of action taken and subsequent outcome. In this way, a comprehensive and ongoing record of the patient's condition and action taken is available on the variance sheets for scrutiny by the clinical team.

Where the patient is free from symptoms at a timed assessment, a single **A** should be documented in the box corresponding with the time of the assessment which indicates that the goal of patient comfort was **Achieved.** If the patient displays any of the symptoms at the time of assessment then a single **V** should be documented in this box which indicates a **Variance** (ie that the patient comfort was not achieved). A corresponding entry should then be made on the variance sheet detailing the nature of the discomfort, and an explanation of the action taken and the subsequent outcome.

If you have any problems or concerns re this LCP Data dictionary please discuss with the LCP Resource Nurse.

References:

LCP Central team UK, Liverpool Care of the Dying Pathway (LCP). (July 2008).*Goal Definitions/Data Dictionary*, The Marie Curie Palliative Care Institute.

For more information go to Marie Curie Palliative Care Institute Liverpool website http://www.mcpcil.org.uk

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