After-hours palliative care framework

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Contents

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Access to after-hours support has been a requirement for all Victorian community palliative care services since 1997. The Department of Health's *Policy and funding guidelines* define business hours as normally falling between 7 am and 4.30 pm Monday to Friday, not including public holidays. All other times are 'after-hours'. The guidelines describe the minimum level of service for after-hours community palliative care including:

- telephone advice to carers and families primarily (but not only) about symptom management if required
- a nursing visit if the service assesses that a visit is required and it is safe for staff to undertake the visit.

Any other after-hours support negotiated between clients and the community palliative care service is on an individual basis.

Community palliative care services will ensure the phone number for an after-hours service which is appropriately staffed is provided to all clients and carers upon admission to the community palliative care service. To ensure the safe and effective delivery of after-hours services all community palliative care services will have:

- a multidisciplinary care planning process that anticipates and addresses the need for after-hours palliative care
- a policy and procedures regarding access to medications after-hours
- occupational health and safety procedures and equipment for staff undertaking visits after hours (in accordance with *WorkSafe's Working safely in visiting health services*, June 2006).

The guidelines also state that these policies and procedures should be included as part of a palliative care consortia-wide framework for after-hours palliative care.

> Palliative care consortia were established in 2004 in all departmental regions. The role of the palliative care consortia is to:
>
> - undertake regional planning in line with departmental directions
> - coordinate palliative care service provision in each region
> - advise the department about regional priorities for future service development and funding
> - in conjunction with the Palliative Care Clinical Network
>   - implement the service delivery framework
>   - undertake communication, capacity building and clinical service improvement initiatives.

Strengthening palliative care: Policy and strategic directions 2011–2015 identifies increasing the availability of after-hours support to clients and carers in their homes, particularly in rural areas, as a key priority. The policy also notes that palliative care consortia are responsible for coordinating after-hours palliative care across their region.

In addition, the *Service delivery framework* identifies the provision of on-call or other after-hours support by medical staff with experience in palliative care as a requirement for inpatient palliative care services (levels 2 and 3), and after-hours support as a requirement for all community palliative care services.

> The World Health Organization describes palliative care as an approach that 'improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (World Health Organization 2010).

Background

Prior to 2007 there was no clear agreement about the most appropriate model of after-hours palliative care for Victoria. In March 2009 the department funded two pilot projects to identify the models and elements of an after-hours service that could be rolled out to other services across the state.

The first pilot project comprised services from Eastern Metropolitan Region Palliative Care Consortium (one service), Barwon-South Western Region Palliative Care Consortium (one service) and Hume Region Palliative Care Consortium (five services). This project's objective was to develop a regional framework for delivering after-hours palliative care services that used an existing telephone triage service based at Caritas Christi Hospice.

The second pilot project comprised services from Grampians Region Palliative Care Consortium (four services) and Loddon Mallee Regional Palliative Care Consortium (seven services). The project's objective was to develop an after-hours palliative care service model appropriate for rural areas.

The *After-hours palliative care framework* ('the framework') is informed by the findings of the pilot projects. It is designed to assist palliative care consortia and palliative care services to develop models of after-hours support for their region. The framework includes:

- resource documents (such as telephone protocols, frequently asked questions and sample templates)
- information technology (IT) specifications
- literature review.

The framework

Implementing a model for after-hours palliative care can create significant challenges and significant benefits to palliative care services. Successful implementation is reliant on good project management, administrative/clinical support, consistent principles, ownership, service-specific strategies and integration of existing processes.

Constant communication between all parties involved is essential. This can be achieved through working parties, regular road trips and site visits, team meetings, teleconferences, workshops, consortium meetings, emails, visual summaries through flow charts, monthly updates, encouraging feedback/comments from all parties and celebrating achievements.

> A key component of any model of after-hours palliative care is having a focus on educating clients and carers, particularly during business hours, on symptom management and providing clients and carers with written plans to assist them in managing situations that may arise.

The development and implementation of a model for after-hours palliative care will be best achieved if community palliative care services:

- identify an internal 'champion' who is provided with time release to coordinate the implementation of the model and liaise with the consortia for project management support
- increase the emphasis on symptom management and education of clients and carers during business hours
- conduct statistical analysis of after-hours calls
- identify service capacity to provide after-hours home visits
- scope existing local and regional infrastructure to identify the most appropriate option for the service delivery of after-hours telephone triage
- allocate sufficient funding to ensure after-hours telephone triage staff are supernumerary to support significant client numbers
- explore relationships and conduct regular meetings between palliative care services and other health providers and potential partners.

Some palliative care services may encounter challenges in implementing a model of after-hours palliative care. Services are often time poor and may find it difficult to allocate sufficient time needed to implement change into their service. Services will have existing procedures and staff may not recognise a need for change. Budget uncertainty and staffing uncertainty may negatively influence services' willingness to participate in the process.

However, in order to ensure 'ownership' of the model, all levels of staff and service management should be involved in developing and implementing the model. Palliative care services must recognise the need for implementing a model of after-hours palliative care, participate in the development and implementation of the model, and agree to discuss issues as they arise. Finally, it is important for clinicians to recognise that by creating a sustainable model of after-hours palliative care that enables current practices to continue to evolve, clients and carers will be better supported.

Three alternative models of after-hours palliative care that provide local solutions are:

1. a regional after-hours nursing telephone triage service provider supporting several community palliative care services
2. a local hospital after-hours manager providing telephone triage to the local community palliative care service
3. an individual palliative care service or local district nursing service providing after-hours telephone triage support to the local community.

Key elements of an after-hours palliative care model

Six key elements have been identified to form the basis of a model of after-hours palliative care. They encompass: client care planning; electronic and paper-based client information systems; after-hours telephone triage (staff, processes and tools); after-hours nursing; after-hours medical support; and activities following an after-hours contact including quality assurance activities.

> Clients and carers are most likely to seek advice from an after-hours palliative care service in relation to queries about medication, nursing advice, pain relief and anxiety.

Element 1: Best practice care planning

Best practice care planning should include the following core inputs.

Client care plan (minimum requirements):

- date
- client issue/problem (by symptom category)
- issue problem goal or desired outcome
- issue action plan/action
- Registered nurse (RN) name and signature
- target/review date
- outcome, date, signature or initial
- advised of 24-hour advice line.

Client care plan (desirable requirements):

- clinical assessment form: education, referrals and outcomes as agreed by symptom
- client-held symptom management guideline identifying current PRN medications
- version number
- service/discipline responsible/team members involved (interdisciplinary)
- indication of carer involvement in development of care plan including a line for client and witness signature and dates and verbal consent by client/carer
- indication if client/carer given a copy
- who to contact for help (for example, during business hours, after-hours and for respite care advice, pain, nausea and vomiting, bowels, equipment, hygiene assistance).

> The Victorian Government's *Service coordination tool templates* (SCTT) are a suite of templates developed to facilitate and support service coordination. The SCTT support the collection and recording of initial contact, initial needs identification, referral and coordinated care planning information in a standardised way. Using the SCTT can improve communication between service providers, the recording of information generated by screening and assessment processes, information sharing, and the quality of referrals and feedback between service providers. This can assist service providers to share relevant information to support better outcomes for clients.

Team/client care planning:

- care planning standards included in local policy
- individual client care plans discussion during interdisciplinary team meetings including
  - identification of actual and potential client symptoms, crisis and other issues
  - agreement on how to manage these issues (including allied health, education, referrals and desired outcomes)
  - agreement on action to be taken where the carer is no longer coping with home care or there is a medical problem requiring hospitalisation
- nursing and medical staff are aware of the limits of the after-hours support in their region
- client and carer are provided with a copy of the care plan and any additional written instructions/resources on how to manage symptoms and crises
- quality assurance processes check the adequate completion and appropriate content of care plans.

Carer/family care planning:

- family meetings offered and completed shortly after admission to enhance assessment, service information provision and initial care planning
- client's care plan to include the identified needs of the carer and strategies that utilise the skills of the interdisciplinary team and external community services
- home record folders to contain care plans and information provided for easy communication between services including the general practitioner (GP).

Advocacy for improving access to medications

- If the client does not have a nominated GP on admission, community palliative care service to work with the client to identify a suitable GP.
- Communicate client information to the client's nominated GP via verbal and written means, and ensure the GP has information regarding key online palliative care resources.
- Palliative medicine specialists support GPs not confident with prescribing palliative medications.
- Working in conjunction with the client's primary and tertiary doctors, supply timely and appropriate medication in the client home, or arrange alternatives where these are not available, based on actual and potential symptoms and care needs.
- Use community pharmacists for client medication education, review and client care planning.

Advance care planning

- Palliative care websites to provide links/information about advance care planning.
- Advance care plan information within client assessments to include
  - preferred site of care
  - preferred site of death
  - client to be admitted to hospital for symptom care, respite care, terminal care
- Provide all clients with information on advance care plans.
- Help clients complete an advance care plan based on the principals of informed consent and help clients communicate the plan to their family.
- Palliative care services provide clients with a written care plan (including verification of death process).

> Advance care planning (ACP) is the process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision making at a future time when that person cannot make or communicate his or her decisions. ACP plays an important role in ensuring that people's wishes at the end of their lives are discussed and documented. It is preferable that advance care plans have been developed by individuals and their families before the need for palliative care arises.

Element 2: Client information systems

Client information systems should include the following core inputs.

Client information systems and electronic functionality (minimum requirements):

- client name, date of birth, age, address, telephone number(s)
- next of kin or carer name, telephone number(s), relationship status, location (address)
- client alerts, cautions, risk management (including ACP information)
- allergies and medications (current and ceased, dose, route, frequency, PRN, emergency, in place/ current order)
- GP's name, telephone number (business hours, after-hours), level of care (elected to provide)
- client diagnosis, medical history, phase of illness and complexity of care
- client treatments
- key symptoms with severity 1–10
- notes or contact record/last note recorded including author name and designation
- initial client assessment
- client expectations of care, preference for site of care and approach to end-of-life care including any ACP/directive or medical power of attorney.

Client information systems and electronic functionality (desirable requirements):

- nominated people who can be called on behalf of the client
- client's preferred name, gender, pension/DVA status, health care card holder status, Medicare number, health insurance status, country of birth, Indigenous status, need for interpreter services and preferred language
- current client care plan/symptom action plan
- client's understanding of the disease process and prognosis
- client's inpatient admissions
- Edmonton chart (all relevant symptom scores over time)
- client's community team and district/community nursing round
- regional after-hours service contact numbers including on-call nursing and medical staff and appropriate contact/referral/admission guidelines
- frequently used regional contact numbers list
- client's current location (for example, acute inpatient, inpatient PCU or other respite care)
- client's oncologist/specialist and definitions/abbreviations list
- correspondence such as hospital discharge summaries and GP letters
- guidelines regarding contacting a client/carer when contact number(s) fail or what to do if contact cannot be made
- information about local advance care plans and how to best support decisions about preferred site of care/death
- other health professionals (such as allied health, hospital outreach workers, community pharmacist).

Where client information is mainly paper based the information shared with an after-hours service should be sufficient to allow for nursing and medical decision making. This includes the placement of care plans, symptom management guidelines and medication orders in the home.

Electronic client information systems (minimum functionality):

- remote (web based) accessibility for business hours and after-hours users
- speed
- ease of use (such as uncluttered formatting of client summary and assessment information and clear client search option(s))
- secure and confidential
- centrally hosted.

> The benefits of electronic client information systems include:
>
> - quick access to legible and up-to-date information
> - information regarding the client's condition, the latest plan and assistance given to them
> - a clear picture of the client's current status and symptoms at a glance prior to speaking with the client.

Electronic client information systems (desirable functionality):

- search options to include search screen as default for triage nurses after log in, search field at the top of any 'review' or 'client list' page, automatic cursor location in the search field, alphabetical automated drop-down client list, enabling the Enter/Return key to commence loading once the correct client is selected
- action icons (indicating searching/loading/saving in progress)
- an Edmonton chart
- access to all required client information within two mouse clicks from individual client summary/review page
- reporting system for software errors
- internal notification system for after-hours contacts
- integration with existing systems.

Element 3: After-hours telephone triage

After-hours telephone triage services aim to:

- provide continuity of care, as well as professional information, comfort and support after hours for clients and carers
- empower clients and carers to confidently use palliative medications and practices to enable clients to remain at home at the end of their life if this is in line with their preferred place of care and death
- reduce unnecessary use of after-hours on-call nursing visits and medical, ambulance and acute medical services (presentations at emergency departments)
- maximise accessibility, effectiveness, client and staff safety and the appropriate use of human resources
- provide an acceptable and appropriate service based on standardised symptom assessment, expert palliative care home treatment advice, appropriate referrals, information and education to enhance client/carer coping and resilience and responsive crises intervention
- add to the national and international bodies of evidence about provision of after-hours support.

After-hours telephone triage services should include the following core inputs.

Service design

Systematic design and evidence based, using best industry practice and clinical tools including:

- clearly defined and agreed aims and objectives and service contracts
- compliance with applicable government palliative care policy and standards
- dedicated specialist staff provided with a dedicated phone line and office
- adequate time and resources, including administrative support
- staff required to undertake clinical telephone triage training and professional development activities related to palliative care
- a system to guide call responses based on regional service availability and symptom assessment
- the ability to access advice from other healthcare professionals when needed
- formal clinical governance processes including a service quality review and development, staff appraisals and management feedback to staff.

Contracts between an after-hours service and a regional community palliative care service should include expectations/provisions regarding:

- the services to be provided (such as hours, staffing, regional after-hours processes)
- geographic service area covered
- client information (such as confidentiality, electronic client information systems or paper-based information systems)
- contract length
- contract price
- contract review/renewal timeframe
- reporting procedures
- client/carer follow-up process and procedures
- data reporting requirements
- the agreed process for using/billing for telephone interpreters when requested by callers.

Skill set and orientation guidelines

The skill set required by an after-hours support nurse should include:

- assertive clear communication
- active listening skills
- interpersonal skills (counselling, empathy, advocacy)
- palliative care symptom management knowledge and clinical experience
- advanced general, oncology or community nursing experience
- intuition and ability to think broadly and respond quickly
- enjoys working autonomously
- ability to delegate key tasks
- administrative and applicable clinical management experience
- competent computer skills.

After-hours service duties, responsibilities and key skills to be clearly outlined in the after-hours service nurse's position description to assist during the recruitment processes.

After-hours support nurses' orientation to cover:

- overview of the after-hours service
- client after-hours service access process(s) (pager/mobile/problem solving)
- overview of the relevant community palliative care services
- education on common caller issues and outcomes
- internal data management training and practice
- regionally specific education including
  - service background and operational structure
  - assessment frequency, client/carer education and care planning
  - electronic client information systems training and practice (including checking for alerts)
  - available local after-hours resources
  - on-call nursing and specialist medical staff
  - local hospitals, hospices, GP/locum and pharmacy services
  - training and defined role of the visiting district/community nurse
  - management of clients in residential facilities
  - when and why to make referral calls
  - general expectations regarding the after-hours service
- supernumerary shifts with after-hours staff and regional staff to observe the existing processes
- study of relevant literature, guidelines and case reviews.

Staff resources and training:

- staff given direction to and provided with relevant paper-based and online information and education resources including textbooks, journal articles and best practice local, national and international government or non-government online resources
- staff access to palliative care information, training and workshops
- staff access to guidelines outlining agreed best practice call management and documentation, symptom assessment and responses to frequently ask questions to assist in the provision of a more standardised, equitable and quality service
- staff access to agreed regional policy/guidelines that cover
  - establishing on-call staff details
  - access to client information
  - telephonic and IT processes and problem solving
  - triaging a client and associated problem solving
  - regional after-hours support (telephone triage and triggers/processes for referrals to other healthcare providers)
  - managing client refusal of advice
  - client and staff actions following a call
  - documentation and daily/monthly reporting
  - reporting of issues/complaints and staff debriefing

- staff training or professional development activities to include
  - needs-based and prioritised learning objectives regarding knowledge/skills/attitudes
  - evaluation based on these objectives
  - evidence-based teaching methods
  - advanced palliative care nursing and after-hours support training including
    - telephone triaging skills
    - cultural competence
    - demographic profiles of palliative care clients and carers/regional variances
    - after-hours call trends (reasons and outcomes)
    - advanced pharmacological and non-pharmacological symptom management strategies
    - identifying palliative care emergencies
    - leading after-hours support/working with district nursing teams
    - case reviews (description of clinical situation, exploration of specific practice problem, contributing/causative factors, alternative strategies to enhance outcomes)
    - problem solving where a situation is outside the scope of accessible guidelines
    - stress and grief.

Community palliative care services (minimum requirements):

- written information for clients and carers about the after-hours services provided, including telephone triage, to create realistic expectations and encourage patronage and correct use of the services available
- assist clients or carers with sight, speech or hearing impairments to enhance their ability to access the after-hours service
- encourage clients and carers to refer to the care/symptom management plan provided by the palliative care service when accessing the after-hours service.

Element 4: After-hours nursing support

After-hours nursing support should include the following core inputs.

Triggers for after-hours nursing visits:

- Triggers should be agreed with the visiting nursing service and may include:
  - a client death
  - three breakthrough doses of medication have been used as prescribed and symptom(s) are persisting
  - multiple calls received from a client that day/evening/night and no progress on the issue(s) at hand has been made
  - the client and/or carer is too distressed to keep managing on their own
  - any other reason identified by the after-hours service.

Visiting services

- Extra planning is required for the after-hours support of clients in residential care facilities.
- Regional district or community nursing services providing unplanned after-hours visits to clients during weekend and public holiday day and evening shifts should analyse the frequency with which these visits occur and plan available time in their daily schedule for the potential for these unscheduled visits.

- The tasks visiting nurses are allowed to undertake after hours must be outlined in position descriptions and local policy and these should be made available to the after-hours service.
- Visiting district/community nurses should:
  - be actively encouraged to undertake palliative care education courses and study days, with updates throughout their career
  - be resourced with palliative care information
  - be made aware of the home record folders, symptom management guidelines and care plans.

Visiting service risk assessment

- A formal home-visiting risk assessment is to be completed for all clients. A management plan should be created for any risks identified and alerts to this information should be available to after-hours service staff.
- Risk/safety assessments to include:
  - client and/or carer consent to home visits
  - client medical risks
  - telephone access (land line, health service mobile phone coverage)
  - verification, categorisation and description of dwelling
  - access notes/issues (specific direction, road quality, street signage/lighting, house/number visible from street, operational/automatic lighting, well-maintained fences/gates/gardens/grounds, close parking, clear entry/exit door(s), pathways safe/non-slip/uncluttered, well-maintained drainage and waste bins, occupant(s) ability to answer door/need for alarm/lock-up system)
  - outdoor lighting and exit routes
  - client/occupant history of violence/aggression/drug use/mental illness
  - family conflict
  - cultural needs
  - any weapons are secured in locked cupboard
  - animals present/clients agree to secure away during visits
  - manual handling hazards (furniture height, client needs for transfer/care, adequate space, hazardous manual tasks required, level floor surface)
  - risk management pathway for identified hazards (client negotiation, discussion with supervisor, outcomes).

Relevant home visiting guidelines (minimum requirements):

- organisational/staff responsibilities and rights relating to after-hours visiting processes including
  - legal duties (such as duty of care, code of conduct, verification of death and scope of practice)
  - commitment to controlling hazards and minimising risks
  - staff orientation and training
  - individual actions prior/during and after a home visit
  - staff right to refuse to visit
  - on-call entitlements and agency/service reimbursements
  - staff support, debriefing and leave after an incident
- on-call service client eligibility (where after-hours visits not available to all clients)
- steps to be taken for risk assessment and risk planning/management

- after-hours equipment/cleaning/return/replacing lost items
- after-hours car availability/safe use/return
- management of S8/S11 drugs in the home
- communicating and interacting with the after-hours service (including failure of communication/pager service)
- violence and aggression management (including cognitively impaired persons; dementia/delirium management, defusing threats/back-up/reporting/retreat/armed threats)
- after-hours problem solving (such as a flow chart for clients refusing advice or requiring medical review/admission to a care facility/access to or administration of medications/an interpreter/post-death procedures)
- verification of death
- no lift (policy, processes and yearly competencies)
- incident reporting
- bushfire safety.

Element 5: After-hours medical support

After-hours medical support should include following core inputs.

Support for clients (minimum requirements):
- palliative care services to arrange their own on-call palliative care medical support or have alternate processes where this is not available (local or regional/metropolitan agreements)
- regional information and communication technologies
- formalisation of plans for when regional colleagues go on leave
- improved education of community teams and those visiting/requesting advice after hours
- improved communication and dissemination of client information including the use of e-health records and common assessment tools
- provision of additional consultants or sharing of on-call support with adjacent regions
- all medical officers working after hours with clients, including GPs, to have access to formal debriefing and support services
- all medical officers working after hours with clients, including GPs, to be made aware of the after-hours services available and not available in their area.

After-hours/on-call nurse contact with medical officers

On-call specialist palliative care medical input is required after hours for clients where:

- contact with the client's GP/locum has been attempted and the GP/locum is not available or unable to manage the case alone
- medication order clarification is required (use, dose and frequency)
- there has been a change in client condition requiring expert management or medication change/advice, including where commencement of a syringe driver is required or an intervention such as insertion of an indwelling catheter or rectal suppositories are required
- all available symptom relief measures have been used and the client is still experiencing symptoms
- there are signs of a febrile illness or other reversible medical condition/palliative care emergency
- other medical officers wish to discuss clients/medications with a palliative care doctor

- the client or carer wishes for the client to be transferred to an inpatient facility for care
- the after-hours nurse/call nurse are not able to resolve client issues/the caller has refused to comply with their advice
- the after-hours nurse/on-call nurse wishes to check if advice to attend an emergency department is the suitable course of action.

After-hours advice to seek urgent medical attention

- Triage staff will advise the caller to contact the ambulance service and/or attend the local hospital emergency department where
  - the client's GP/locum is not able to visit or visit within the required timeframe
  - an on-call nursing visit is not available
  - there has been a fall or change in client mobility resulting in a need for physical assistance and assessment for symptom management
  - appropriate emergency medications are not ordered or in the home and are urgently required and not accessible after hours
  - there is a new and unexpected symptom requiring urgent assessment such as acute respiratory distress, extreme pain, uncontrolled vomiting, haemorrhaging, a suspected fracture, chest pain, disturbing behaviour or risk of dehydration
  - a palliative care emergency unable to be managed in the home such as spinal cord compression
  - clients on chemotherapy becoming acutely febrile
  - the client situation does not allow time to wait for an on-call doctor
  - the carer/family or client is not coping with client care at home and experiencing major stress despite support provided by visiting nurses.
- After-hours staff to have access to guidelines regarding when they need to contact the ambulance service on behalf of a client (complex cases or where it is felt that the caller will be unable to do so effectively).
- The after-hours service to call ahead on behalf of any clients referred to their local emergency department to give a handover of their palliative status and current acute medical or care needs.
- After-hours service medical handover (to the ambulance service and/or local hospital emergency department) to include
  - client's details (name, date of birth, language spoken, need for an interpreter, diagnosis)
  - client's contact information
  - pension number or health insurance status
  - next of kin or medical ensuring power of attorney (or equivalent) and their contact details
  - reason for ambulance/acute services – current issues
  - relevant medical history
  - medications and allergies
  - recent treatments and test results
  - usual condition and functioning
  - details of referral support (on-call nursing or medical officer)
  - client/carer wishes and psychosocial situation
  - current observations (as assessed over the telephone and in the home).

Element 6: Activity following an after-hours contact and quality assurance

Activity following an after-hours contact and quality assurance should include the following core inputs.

After-hours staff and on-call staff support and issues management

- After-hours service and on-call nursing and medical staff:
- to be provided with and educated about internal and external, formal and informal debriefing opportunities
- to be periodically surveyed to assess their on the job perceptions and satisfaction levels to feed into staffing support programs
- to identify any regional clinical or staffing issues and communicate these to the after-hours service via a defined issues management process.

Next day communication and follow-up

Details of after-hours contacts to be communicated by the start of the next business day to the community palliative care service via electronic or paper-based means:

- after-hours staff to ideally be able to log the details of any after-hours contacts directly into an electronic client information system, including Palliative Care Outcomes Collaboration (PCOC) data and contact notes, using a unique authorship identifier.

Community palliative care service actions following after-hours contact:

- staff to contact clients using the after-hours service the following business day to assess if there are any outstanding issues and if so attempt to resolve these before the close of business that day
- staff to analyse the events leading up to an after-hours contact and alter the client's care plan accordingly, especially where a client is calling the service frequently but unnecessarily
- management plans for frequent callers should be provided electronically or on paper to the after-hours service for their reference.

After-hours service data collection systems (minimum requirements):

- client's name
- caller's relationship
- caller's name
- call reason
- call date and time
- regional team name
- call outcome
- notes
- call-out details (reason, time start/end, comments).

After-hours service data collection systems (desirable requirements):

- caller identifies as Aboriginal or Torres Strait Islander
- caller has ESL needs
- caller angry/abusive
- triage nurse contact delayed

- number of referral calls or call backs to client
- caller verbalises understanding of instructions given and agrees with action to be taken
- caller agrees to call back if symptoms worsen or caregiver concern increases
- notes on the caller's preferred course of action if they disagree with the advice given
- data capture software to have the ability to produce daily and monthly data reports or raw data tables.

Data collection and quality assurance activities

- Communication and relationship-building activities to take place regularly (annual or six monthly) between regional on-call staff, community palliative care staff and after-hours staff to strengthen professional links and enable case review and debriefing about difficult after-hours scenarios.
- Community palliative care services and contracted after-hours services to agree on the data collection parameters required to feed into ongoing service review and development activities.
- Any programs or data sheets that include client information should be password-protected prior to emailing to ensure confidentiality is maintained.
- Collection, use and disclosure of any personal or health information must adhere to relevant privacy laws (such as *Health Records Act (Vic) 2001*).
- Use of after-hours service data to evaluate:
  - number of episodes and calls made by the triage nurse
  - number and percentage of clients calling from each regional team
  - repeat callers
  - service costs (such as time spent, visits and referral calls made)
  - reason for calls
  - nursing visit data
  - call distribution by day and time of day
  - average call time trends
  - on-call staff inputs (nursing visits, referral calls to nursing and medical staff)
  - call outcomes.
- Use of after-hours service data to monitor and use trends for:
  - service resourcing
  - evaluation of effectiveness of client management by team (during business hours)
  - evaluation of complexity of calls (such as total calls versus episodes, duration of calls, referral calls)
  - triage appropriateness and service effectiveness
  - staff and client/carer preparatory and preventative education activities
  - client profiling
  - after-hours need based on client population profile (phase/complexity of care, diagnosis).
- Universal key performance measures of the effectiveness and efficiency of after-hours services to include:
  - population usage figures (under/over use of the service)
  - service response time of under 10 minutes from time of client contact
  - user satisfaction
  - call issue resolution within a minimum time and number of calls

- referral calls to healthcare professionals
- stable or decreasing trends in nursing visits
- referral to acute medical services/ambulance service
- review of the outcomes of complex cases by service management
- complaints received
- regional community palliative care and district nursing staff ratings of the service.

After-hours telephone protocols

> **Disclaimer:** The *After-hours telephone protocols* are a guide only and may need to be adapted depending on the circumstances.

Call introduction

- *Hello this is* (name) *from the* (service name) *after-hours telephone service.*
- *May I ask your name, phone number, the patient's name and where you are calling from?*
  (If the caller is not the client, enter the caller's full name into the record notes.)
- *May I ask which community palliative care service you belong to?*
- *Which large town or hospital do you live near?*
- *Can you please wait a moment while I locate your information?*

All:

- *Do you require a telephone interpreter to be arranged?*
- *Do you identify yourself as being of Aboriginal or Torres Strait Islander descent?*
- *Have you contacted this service before?* (if caller not recognised)
- *What is your relationship to* (client's name)?
- *Is* (client's name) *with you at the moment?* (If not, note where the caller is in relation to the client.)
- *Have you got* (client's name)'s *folder and medications there to refer to?* (If not ask to collect both before proceeding.)
- *How can I help you?*

Where the client has died: see Death at home protocol

If the call is regarding an unregistered patient:

- *Unfortunately you aren't currently registered with the palliative care service or haven't been assessed yet. I will try to help, but what I can offer will be fairly limited.*
- Ask where they got the after-hours triage number and document that the caller is unregistered at beginning of the record notes.

If you need to postpone a non-urgent triage call:

- Inform the caller that you are unable to take their call at this time due to (for example, other urgent calls).
- Nominate the earliest time that you would be able to call them back.
- Document the time of the first call and the reason for the delay.
- Undertake to phone the caller back by the promised time.

Assessment and advice

- *I'm just going to ask you a few questions then I will give you some advice on the best plan of action. Is that OK?*
- *I am quite willing to repeat any information so please let me know if this would be helpful.*
- *First, do you have an action or care plan in your home folder or diary that you can refer to during our conversation?*
- (If yes) *What does that say to do for* (x issue/symptom)?

- *When were you last seen by a nurse or doctor? What did they say to do for* (x issue/symptom)?
- *Are the symptoms new and how severe are they?*
- Go from most to least acute issue/symptom.
- Refer to <www.health.vic.gov.au/clinicians> for relevant therapeutic guidelines, CCH texts and MIMS on the Clinicians Health Channel.
- Encourage the use of 2–3 x oral breakthrough medication as prescribed (if appropriate) and order PRN before the use of injectable medication/a nursing visit.
- Ask to speak with the client directly to more accurately assess their issues/symptoms.
- If you cannot understand the caller or vice versa, ask if there is someone else available (neighbour, family, friend) who could call or be put on the phone or arrange a telephone interpreter.
- What is the general condition of the patient and what are the patient/family's wishes?

Psychosocial support and health education

If the carer sounds like they aren't coping ask:

- what they are finding most difficult at the moment
- what information they need now
- what local/written/online resources they are aware of
- if they need help accessing these or other resources.

The after-hours triage service is not a counselling service. For more detailed counselling refer callers to Lifeline 131 114, Griefline (03) 9596 7799 or the Cancer Helpline 131 120.

Referrals

(Does their GP visit after hours?)

- *I would recommend you see a doctor for (x reason) as soon as possible. Please call your GP/ contact the locum service/call '000' for an ambulance/attend your local emergency department when you hang up from me.*

or

- *I would recommend you see your (GP/specialist/other healthcare provider) within 24–48 hours for* (x reason).

or

- *I will ask the staff at* (community palliative care service) *to follow this up with you* (tomorrow/next business day).

or

- *I will get in touch with the nurse on-call in your area, discuss this call with them and ask them to come out and visit for* (x reason). *I will call you back with the approximate time of their visit if they agree they need to attend, otherwise they may phone you directly.*

Advise the caller that you are available to liaise with their GP/attending locum/the ambulance service if required.

Ask which hospital they will be attending. Advise the caller that you will call ahead to inform them of the pending arrival.

Where the caller needs to see a provider, such as attend their local emergency department or see a doctor in the next 24–48 hours, consider:

- if the caller knows where to go
- conducting an online search for local services
- confirming if the service is open
- providing details for the appropriate service.

If an ambulance is required, the caller needs to contact emergency services themselves. Families and carers need to take their medications with them and let staff know that the client is receiving palliative care and what the client's wishes are in terms of treatment.

Phone the relevant hospital triage and provide them with the client's details, clinical information and rationale for their presentation.

Concluding the call

- *Do you agree with the advice I have provided?*
- (If no) *Can you please tell me what you plan to do instead?*
- Document what the caller intends to do, reiterate the reasons for your advice and advise the senior nurse and/or clinician on-call of the caller's refusal to comply with the advice provided.
- (If yes) *Can you quickly repeat the plan to me so I can make sure you've understood everything we've discussed?*
- *Please call back anytime you need to/if you feel* (client) *is the same or worse in* (x minutes/hours)/ *if you have any ongoing concerns*.
- Reinforce if you feel immediate medical attention is advised.

If the call was regarding a general enquiry/daytime service coordination:

- *For future reference* (community palliative care service) *is open from* (Monday to Friday, x am to x pm). *Please try to call within these hours for any general enquiries so we can save this line for emergencies.*
- *Thank you for calling*. (Let the caller terminate the call first.)

Difficult/angry callers

- Remain as calm as possible with a caring or neutral tone and pitch.
- Use open-ended questions. The longer the caller talks, the more difficult it is for them to maintain an angry tone.
- Listen carefully and give your full attention to the caller. Don't interrupt the caller. Pause after they finish before replying.
- Repeat the caller's problem back to them; empathise but don't apologise; paraphrase their point ('*That must be very upsetting*').
- Reassure the caller you will do your best to resolve the situation that has caused them to be angry.
- Avoid saying, '*You should* …' near the beginning of your statements. Instead use phrases such as '*You might… or 'I suggest trying…*')

- Don't say 'I'm sorry' as this is an admission of guilt. You can apologise for the caller's inconvenience or regret their dissatisfaction. Use phrases such as '*I see what you mean*', '*That must be very upsetting*', '*I understand how frustrating this must be*'.
- Don't make empty promises. Tell them only what you can and cannot do.
- Seek the caller's permission to involve others to resolve the problem.
- Check that the caller understands and accepts the actions you propose to take.
- Invite the caller to put any complaint they have in writing to the relevant palliative care service.
- Make notes about what was said from both sides so you can document the conversation fully in the client notes and respond in full to any future complaints lodged by the caller.
- If the caller is repeating themselves and you have helped as much as possible say, '*We have been through this information already and we don't seem to be going anywhere. Perhaps you should think if there is anything further you wish to ask and then call us again. I am now ending the call*'.

Abusive callers

An abusive caller speaks to you in a way that makes you feel uncomfortable and/or makes comments of a derogatory nature.

- Remain polite, professional and empathetic.
- Explain why their behaviour makes you feel uncomfortable.
- Let the caller know that if the behaviour doesn't stop then you will terminate the call.
- Reassure them that you are happy to help them if the behaviour stops.
- If the abuse continues after a clear warning, hang up.
- If the person calls/pagers back, call them and ask them if they are prepared to be calm. Remind them you will hang up if they repeat the behaviour of the previous call.
- Get a colleague to listen into the conversation and take notes.

Evasive callers

- Reassure the caller the service is confidential.
- Try to ascertain why the caller is not willing to provide the information you require.
- If you have insufficient information to answer their question it is acceptable to refuse to answer their enquiry or advise the caller the answer you provide will have limitations.

Persistent callers

If you have helped the caller as much as possible:

- Tell the caller you must go to answer other calls as people are waiting.
- Tell the caller you have other work to attend to.

Pain

This section is to be used where the patient has pre-existing pain and needs to be encouraged to seek medical advice when a new pain develops.

Key questions:

- What is the patient's medical history (diagnosis, secondaries, pain score history), recent alerts/notes, recent treatments, recent accident/injury, phase of care?
- Where is the pain (internal/external, stationary/radiating)?
- Is this new pain? When was the onset? Is it constant or does it come and go? Is it escalating?
- Can the patient score the pain out of 10? At its best? At its worst?
- Can the patient describe the pain (for example, dull, sharp, stabbing, unbearable, cramping, burning, exhausting, pins and needles, throbbing)?
- What, apart from medication, makes the pain better or worse (walking, moving, eating, time of day, heat/cold, lying still)?
- What medication does the patient normally take for pain relief? Has the medication regime changed recently?
- Does the patient normally use breakthrough medication? How many breakthroughs have they taken today? Have they reduced the pain?
- Is the patient able to take this medication orally or is it administered at home by other means?
- Assess bowel, nausea/vomiting, anxiety, breathlessness, urinary retention, anorexia, fatigue, ability to carry out ADLs.
- What does the patient want in terms of pain control? (weigh up analgesia with alertness, for example.)
- Is the carer or patient distressed by the pain?

Education:

- Take regular/breakthrough analgesia as currently prescribed (only advise PRN doses if ordered PRN). PRN medication should be 1/6 or 1/12 the daily dose. Consider the use of PRN medication for anxiety/restlessness, nausea and vomiting or constipation. Paracetamol four times daily can be useful where appropriate (if not on Panadol Osteo or suffering from liver/renal impairment).
- Use a diary to track the pain and keep a record of its effectiveness and the side effects of analgesia. Follow a bowel regime. If waking at night, take breakthrough doses before going to bed. Pre-medicate an hour before anticipated painful events.
- Use adjunct measures to reduce pain and anxiety (imagery/distraction/relaxation techniques, massage, changing position, heat or cold on area of origin (avoiding transdermal patches/radiotherapy sites), social activities, music/reading/television).
- Explore the patient's concerns about their pain (what do they think is the cause/meaning).
- If the pain is not settled with one hour of two to three breakthrough doses, or if the patient/carer/family are too distressed to manage at home, further action can be taken (home visit, palliative care medical specialist contact, GP/locum, emergency department).

Refer to PCV pamphlet on pain at <http://www.pallcarevic.asn.au/media/1219725947125-0756.pdf> or information under <http://www.pallcarevic.asn.au/general-public/painsymptom-managementhttp://www.pallcarevic.asn.au/general-public/painsymptom-management/>.

Breathlessness

This section to be used where the patient has known breathlessness, pleural effusion, heart failure, chronic obstructive pulmonary disease (COPD), pneumonia or a tumour obstructing the airways.

Key questions:

- What is the patient's medical history (diagnosis, dual diagnosis, chronic breathing problems/airways disease/CCF, home oxygen, effusion, anaemia, anticoagulation/PE), alerts/notes, recent treatments, phase of care?
- Is this a new symptom? When was the onset? Is it constant or does it come and go? Do they have other cold/flu symptoms?
- Can the patient score the breathlessness out of 10? At its best? At its worst? Is the patient able to talk or achieve any level of activity?
- What, apart from medication, makes the breathlessness better or worse (speaking, walking, resting, lying down, standing, sitting upright with pillows, lying one side as opposed to other, the weather/temperature, television/radio/music, open window and/or fan, calming talk, breathing exercises, use of a humidifier)?
- If this breathlessness is related to the patient's disease, has a hospital admission been necessary previously (for transfusion, tap, dieresis or similar)?
- What medications does the patient normally take for breathlessness? Has this been effective today? Has the medication regime changed recently?
- Is the patient able to take this medication orally/nebulised or is it administered at home by other means?
- Assess for infection/fever, obstruction, uncontrolled pain, anxiety/confusion, cough/cough reflex/secretions, wheeze/strider, fluid retention/overload, alertness/fatigue/headache, heart rate, ascites.
- Is the carer or patient distressed by the breathlessness?

Education:

- Take regular respiratory/anti-anxiety/pain medication as currently prescribed (only advise PRN doses if ordered PRN). Medications to prevent secretions should be used as soon as possible. Also consider the use of PRN medication for anxiety/restlessness.
- Use oxygen if it has been prescribed and is in the house. Oxygen and air can reduce the subjective sensation of breathlessness regardless of hypoxia being present. Consider suction if available.
- Reassure and educate the carer on breathlessness.
- Try using one or some of the non-pharmacological therapies mentioned. Breathing exercises include consciously working to expand the abdomen or breathing in through the nose and out through pursed lips. Avoid symptom triggers/irritants (such as cold air, smoke, humidity), and pace and prioritise activities.
- Record episodes of breathlessness, their intensity (1–10) and self-interventions, as well as any adverse effects of medications.
- If breathlessness persists and/or if the patient/carer/family are too distressed to manage at home further action can be taken (home visit, palliative care medical specialist contact, GP/locum, emergency department).
- Refer to information under <http://www.pallcarevic.asn.au/general-public/painsymptom-managementhttp://www.pallcarevic.asn.au/general-public/painsymptom-management/>.

Nausea or vomiting

This section to be used if the patient is experiencing nausea or vomiting. The patient's anxiety may be contributing to this symptom, or the patient has known medications, recent chemotherapy, constipation, bowel obstruction or cerebral secondaries.

Key questions:

- What is the patient's medical history (diagnosis, cerebral secondaries, diabetes, anxiety, bowel obstruction, GIT disorders, causes of previous episodes of nausea/vomiting), medication regime, recent treatments (chemo/radiotherapy), recent accident/injury and phase of care?
- Is this a new symptom? When was the onset? What is the frequency, intensity and duration of the nausea/vomiting? Is there associated abdominal pain?
- Can the patient describe the vomit including volume, frequency, colour, smell and force? Is there coffee-ground, old or frank new blood?
- What, apart from medication, makes the nausea and vomiting better or worse, such as medications, eating, smell of food, other smells, pain, standing up or change of posture?
- What medication does the patient normally take for nausea and vomiting? Has this been effective today? Has the mediation regime changed recently? Do they think the medication is staying down?
- Is the patient able to take this medication orally or is it administered at home by other means?
- Assess food and fluid intake over the past 24 hours and look for signs of dehydration.
- Assess bladder/bowel history (approximate frequency, amount, colour, consistency).
- Assess for CNS symptoms and pain.
- Assess for suspected haematemesis/upper GI bleed (internal ulcers, previous bleeds, NSAID use, Warfarinisation)
- Is the carer or patient distressed by the nausea/vomiting?

Education:

- Take regular/breakthrough antiemetic medication as currently prescribed (only advise PRN doses if ordered PRN). Follow a regime of taking prescribed antiemetic medication before and following chemotherapy treatment and before meals. Consider the use of PRN medication for anxiety/restlessness, pain or constipation.
- Take sips of clear fluids or ginger ale as tolerated. Use ice chips or frozen juice chips. Provide regular mouth care. Watch for signs and symptoms of dehydration. Have small, frequent meals – cold, bland, non-spicy/greasy food; avoid extreme temperatures and strong odours.
- Use distraction strategies (music, moderate exercise, relaxation, fan, breathing exercises).
- If nausea/vomiting does not settle within an hour of using antiemetics and/or if the patient/carer/family is too distressed to manage at home further action can be taken (home visit, palliative care medical specialist contact, GP/locum, emergency department).
- Nausea and vomiting will decrease as the patient deteriorates into the terminal phase.
- Refer to PCV pamphlet on nausea and vomiting at <http://www.pallcarevic.asn.au/media/1219725978906-0780.pdf> or information under <http://www.pallcarevic.asn.au/general-public/painsymptom-managementhttp://www.pallcarevic.asn.au/general-public/painsymptom-management>.

Anxiety, restlessness, confusion, delirium or agitation

Key questions:

- What is the patient's medical history (diagnosis, cerebral metastases, previous episodes of delirium, a psychiatric/cognitive dual diagnosis), medication regime, recent treatments and phase of care?
- Is this a new symptom? When was the onset? What is the duration, frequency and intensity of the anxiety/restlessness/confusion? What are the associated behaviours?
- What, apart from medications, makes the anxiety/restlessness/confusion better or worse (such as noise/quiet, environment, food/fluid/mouth care, urination, television/radio/music, sitting upright, night light/lighting, touch/massage, progressive muscle relaxation, cold compress, burning oils, Rescue Remedy, reorientation, support/reassurance from close family/friends)?
- What medication does the patient normally take to help reduce anxiety/restlessness/confusion? Has this been effective today? Has the medication regime changed recently?
- Is the patient able to take this medication orally or is it administered at home by other means?
- Assess food and fluid intake over the past 24 hours.
- Assess bladder/bowel history (approximate amount, colour, consistency).
- Assess for CNS symptoms, pain, fever, metabolic issues (dehydration, hypercalcaemia), cardiac/respiratory function (hypoxia), PUD, substance use/withdrawal.
- Review patient, environmental and familial factors.
- Is the carer or patient distressed by the agitation/restlessness/confusion?

Education:

- Take regular/breakthrough anti-anxiety/sedative medication as currently prescribed (only advise PRN doses if ordered PRN). Consider the use of PRN medication for pain, nausea and vomiting, breathlessness or constipation. Benzodiazepines are best used with caution and with other conjunctive therapies such as haloperidol.
- Try to pass urine or use one or some of the non-pharmacological therapies mentioned above.
- Address potential fluid and/or nutritional deficits.
- Address mental health, existential/spiritual, legal or financial concerns using pastoral care/psychology and or psychiatry/other appropriate professionals.
- If agitation persists and/or if the patient/carer/family is too distressed to manage at home further action can be taken (home visit, palliative care medical specialist contact, GP/locum, emergency department).
- Terminal restlessness occurs in 62–88 per cent of all deaths.
- Refer to PCV pamphlet on confusion and terminal restlessness at <http://www.pallcarevic.asn.au/media/1219726068671-0667.pdf> or information under <http://www.pallcarevic.asn.au/general-public/painsymptom-managementhttp://www.pallcarevic.asn.au/general-public/painsymptom-management/>.

Bowel (constipation)

This section to be used where the patient has known commencement of opioids, history of constipation and/or decrease in fluid intake.

Key questions:

- What is the patient's medical history (diagnosis, medications), recent treatment/surgery, nutrition, ADLs, phase of care?
- Is this a new symptom? Is there any abdominal pain/cramping, flatulence, swelling/bloating, malaise and/or nausea/vomiting?
- How long is it since the patient has had their bowels opened (1–3 days, 3–5 days, more than five days)?
- What is the patient's normal bowel pattern (frequency, amount, consistency)?
- Can you describe the amount, consistency and/or colour or the last bowel motion? Is there pain on bowel movement?
- What medications does the patient normally take for the bowels? Has the medication regime changed recently? Has the patient tried increasing their aperients?
- Is the patient able to take this medication orally or is it administered at home by other means?
- Assess nausea and vomiting (colour, consistency, taste, frequency).
- Assess food and fluid intake over the past 24 hours. Assess level of activity.
- Assess bladder history (frequency, approximate amount and colour).
- Assess for pain, anxiety/confusion, fever, metabolic disturbance/hypercalcaemia, severe impaction and/or constipation, bowel obstruction (mechanical/non-mechanical), spinal cord compression.
- Is the carer or patient distressed by the bowel issues?

Education:

- Take regular and PRN aperients as currently prescribed.
- If the bowels have not been opened for more than two days and there is no abdominal distension and the patient is passing flatus, increase aperients by repeating the normal daily regime.
- Follow a daily bowel regime, especially if on constipating therapeutic agents, including toileting daily after breakfast.
- Increase diet quantity and fibre intake (whole grain, prunes, bran, fresh fruit, raw vegetables) and increase fluid intake if appropriate to 8–12 glasses/day. Limit the use of gas-producing foods (including cabbage, beans and green peppers).
- Increase activity levels as able. Use abdominal massage.
- If the bowels are not opened by late morning the next day contact the palliative care team or GP (change in medications, enema, manual evacuation).
- If constipation persists, if there is abdominal pain, swelling and vomiting and/or the patient/carer/family is too distressed to manage at home further action can be taken (home visit, palliative care medical specialist contact, GP/locum, emergency department).
- Refer to information under <http://www.pallcarevic.asn.au/general-public/painsymptom-managementhttp://www.pallcarevic.asn.au/general-public/painsymptom-management/>.

Bowel (bleed/diarrhoea)

Key questions:

- What is the patient's medical history (diagnosis, medications, anticoagulation, platelet dysfunction), nutrition, ADLs, recent treatment/surgery and phase of care)?
- Is this a new symptom? When was the onset? What is the frequency and volume of diarrhoea? Is there any nausea, cramps, gas, abdominal pain/discomfort or straining?
- What is the patient's normal bowel pattern (frequency, amount, consistency)?
- What is the consistency and colour of the patient's stools during the past 24 hours? Was there any mucus or blood? At what amounts?
- Has the patient been using any medications to treat the diarrhoea? Has this been effective today?
- Has the patient been exposed to anyone with a bowel infection?
- Has the patient recently used laxatives/antibiotics/NSAIDs? Been hospitalised? Are they on any alternate therapies? On chemotherapy/radiotherapy? What/area and when was it last given/treated?
- Assess food and fluid intake over the past 24 hours. Any recent changes to the patient's eating pattern? Enteral feeding?
- Assess for dehydration.
- Is the carer or patient distressed by the bowel issues?

Education:

- Decrease fibre intake (whole grain, bran, fresh fruit, nuts, seeds), eliminate milk and milk products, caffeine and alcohol and avoid greasy, spicy or sugary foods. Eat frequent small meals of cooked fruits/vegetables, rice, lean meats, fish or chicken, bananas, apple sauce or toast. Increase fluid intake as tolerated to 8–12 glasses/day and glucose/electrolyte solutions such as Gatorade or Powerade. Limit use of gas-producing foods (such as cabbage, beans and green peppers).
- Use comfort measures such as heat, haemorrhoid barrier creams. Clean peri-anal area frequently to prevent skin breakdown.
- Discontinue/reduce dosage of offending medications. Take anti-diarrheal medication as currently prescribed (only advise PRN doses if ordered PRN) or as advised by a pharmacist.
- If diarrhoea/bleeding persists and/or the patient/carer/family is too distressed to manage at home further action can be taken (home visit, palliative care medical specialist contact, GP/locum, emergency department).
- Refer to information under <http://www.pallcarevic.asn.au/general-public/painsymptom-managementhttp://www.pallcarevic.asn.au/general-public/painsymptom-management/>.

Anorexia or hydration

Key questions:

- What is the patient's medical history (diagnosis of lung or GIT cancers, phase of care, recent treatment(s), latest notes)?
- Is this a new symptom? When was the onset?
- Assess food and fluid intake over the past 24 hours (description, decreased amount/small amount, fluids only/nutritional supplements, very little or none).
- When did the patient last pass urine (approximate amount and colour)?
- What improves/stimulates the patient's intake?
- What is the condition of the patient's mouth/throat?
- Is the patient still able to take oral medication? Can the patient's medications be administered at home by any other means?
- Is the patient able to talk or achieve any level of activity?
- Assess for pain, nausea/vomiting, bowel activity, anxiety/restlessness/confusion or breathlessness.
- Assess for dehydration or sepsis (thirst, dry mouth/skin, sunken eyes, muscle cramps, weakness, dizziness, confusion, fatigue, fever, nausea/vomiting, weight changes).
- Is the carer or patient distressed by the decreased intake?

Education:

- Take regular medications as currently prescribed, especially for pain, anxiety, nausea and bowels.
- Ensure optimal oral care.
- Limit fluid intake 30 minutes before meals to avoid feeling full.
- Eat small meals 5–6 times a day. Don't wait until hungry, although increase intake when most hungry.
- Simplify meal preparation to minimise tension/anxiety (canned soup, frozen dinners, sandwiches). Involve the patient in menu planning.
- Suggest high-protein/calorie foods (cheese, yoghurt, eggs, milkshakes and supplements) in keeping with comorbidity such as diabetes. Cold foods are sometimes better tolerated.
- Eat somewhere other than the bedroom. Provide companionship. Sit up after each meal for 30–60 minutes to facilitate digestion.
- If anorexia persists and/or if the patient/carer/family is too distressed to manage at home further action can be taken (home visit, palliative care medical specialist contact, GP/locum, emergency department).
- Refer to PCV pamphlets on nutrition at <http://www.pallcarevic.asn.au/media/1219726015296-5508.pdf> and anorexia at <http://www.pallcarevic.asn.au/media/1219726054796-6313.pdf> or information under <http://www.pallcarevic.asn.au/general-public/painsymptom-managementhttp://www.pallcarevic.asn.au/general-public/painsymptom-management/>.

Fatigue or weakness

Key questions:

- What is the patient's medical history (diagnosis, medications, anaemia), recent treatment(s), latest notes, phase of care and social situation?
- Is this a new symptom? When was the onset?
- Can the patient score the fatigue/weakness out of 10? At its best? At its worst?
- What makes the fatigue/weakness better or worse?
- When did the patient last pass urine (approximate amount and colour)?
- When/where is the patient sleeping? Is this different from usual? Do they feel rested after a night's sleep?
- Is the patient able to achieve any level of activity?
- What is the patient's ability to carry out activities of daily living? Has this changed? Any difficulty concentrating? Is the patient showing signs of depression/anxiety?
- Assess food and fluid intake over the past 24 hours. Any recent changes to the patient's eating pattern?
- Assess for signs of bleeding (skin pallor, feeling cold/faint/dizzy, breathlessness, rapid heartbeat, leg heaviness), dehydration or sepsis.
- Assess for pain, hypoxia, medication side effects, anxiety/restlessness/confusion, metabolic disturbance.
- Is the carer or patient distressed by this fatigue/weakness?

Education:

- Take regular medications as currently prescribed, especially for pain, fever, depression, insomnia and anxiety. Consider discontinuing/reducing dosage of medications that may be contributing to fatigue.
- Employ energy conservation strategies: scheduled rest periods, set priorities, pace activities, delegate as necessary.
- Explore restorative therapies and stress management options (games, music, reading, relaxation techniques).
- Increase physical activity as able: shown to promote circulation, increase energy levels, impart a feeling of wellbeing and promote a better sleep pattern.
- Remember 75 per cent of cancer patients experience fatigue; it can exist independently of anaemia, it can be episodic in nature but is often cumulative. It may be treatment related and it is not preventable but can be manageable.
- If fatigue persists and/or if the patient/carer/family is too distressed to manage at home further action can be taken (home visit, palliative care medical specialist contact, GP/locum, emergency department).
- Refer to PCV pamphlets on fatigue and exhaustion at <http://www.pallcarevic.asn.au/media/1219725964468-9428.pdf> or information under <http://www.pallcarevic.asn.au/general-public/painsymptom-managementhttp://www.pallcarevic.asn.au/general-public/painsymptom-management/>.

General deterioration, terminal care or carer stress

Key questions:

- What is the patient's level of consciousness? Are they alert, drowsy or unresponsive?
- Does the patient appear to be comfortable?
- What is the patient's pattern of breathing at the moment? What does the patient's breathing sound like?
- Assess for potential reversible medical problems that may need action using the previous guidance notes.
- Does the carer/family understand the current situation and the patient's prognosis?
- What does the carer/family think is happening?
- Are the patient and carer(s) wishes for the patient to remain at home at this time?
- Are there carers available to help look after the patient over the next 24-hour period or does the carer need respite services?
- Do regular DNS/CN/PC RN visits need to be increased?
- If the patient is unable to swallow, are there medications prescribed/available that can be given under the skin, per rectum or under the tongue?
- Has the carer been given any information by their local service regarding the dying process? This will explain many of the changes the patient may experience.
- Does the carer or patient feel too distressed to cope with the current situation?

Education:

- Administer regular medication as currently prescribed where able (only advise PRN doses if ordered PRN). Consider the use of PRN medication for breathlessness, pain and anxiety/restlessness/confusion. Consider changing the route of medications to subcutaneous and/or commencing a syringe driver if an order exists or obtaining an order for one from an on-call medical officer.
- Maintain a calm and quiet environment with familiar people in attendance. Talk to and touch the patient.
- Keep the room lighting appropriate to the time of the day.
- Explore the carer/family beliefs about a good death and any cultural or religious beliefs around illness and death.
- Explore the carer/family's currently emotional state (for example, fear, anxiety, anger and depression) and refer to the appropriate counselling services (face–to-face or telephone).
- Discuss relevant management of incontinence, pressure area care, mouth care, changes in respiration, noisy breathing and death at home.
- Discuss what to expect if the patient deteriorates further.
- Reassure the carer that as long as they feel able to manage the patient can remain at home. If they feel they cannot manage discuss sending a nurse to visit or contacting the ambulance service or GP/locum.

Death at home

Key steps:

- Are you OK? Do you have someone you can call for support?
- Don't ring 000.
- Do you feel comfortable laying the patient flat with their hands by their side?
- Reassure the caller that equipment can stay with the patient.
- Talk the caller through disconnecting the syringe driver for the nurses to collect when they visit.
- If there is no urgency for the body to leave the house, they can remain overnight if the family is comfortable with this. The family can wait until the morning and phone the GP.
- Has the patient been seen by a medical officer in the past month (if not, the death may need to be referred to the State Coroner).
- Have prior arrangements been made by the day service with the patient's GP or funeral director as to how to proceed?
- Paramedics or RNs can verify death before the body is moved from the place of death to a more appropriate location (by a funeral director).
- Refer to regional policies for special local arrangements (in some rural/remote areas the body can be taken by a funeral director prior to verification if the death was expected).
- The funeral director may require verbal reassurance death has occurred or specific paperwork to be completed by the clinical staff. If the latter is the case and an RN cannot attend, an ambulance may need to be called.
- A medical officer can then complete certification of death at a later time.

Palliative care emergencies

Febrile neutropenia

- Has the patient had recent chemotherapy and a temperature above 38 degrees Celsius? Are they systemically unwell or have other signs of sepsis (vital signs)? Are they at risk of going into shock?
- High-risk patients include those: with haematological malignancy; having myelosuppressive chemotherapy or concurrent chemotherapy and radiotherapy; aged over 60; with comorbidities such as diabetes, bone marrow involvement of cancer, delayed surgical healing or open wounds; with significant mucositis; on steroid dose > 25 mg prednisolone daily; with a history of neutropenia; and/or recent hospitalisation for infection.
- Medical investigations and treatment may include a septic workup (blood, central lines, urine, faeces, sputum, wound swabs, chest X-ray), electrolyte/full blood exam, blood tests and antibiotic therapy.

Spinal cord compression

- Does the patient have advanced metastatic cancer or primary spinal disease?
- Does the patient have increased neck/back pain (worse in bed, with straight leg raise or cough/strain), sensory changes (uni or bilateral weakness in the extremities, tingling in the arms on neck flexing or sensory loss), urinary retention or lax sphincter tone?
- Delays in diagnosis and management may result in permanent loss of function.
- Medical investigations and treatment that may be required are MRI/CT, dexamethasone, analgesics or nerve blocks, radiation or chemotherapy or surgery.

Superior vena cava obstruction/syndrome

- Does the patient have an expanding tumour in the upper thorax, particularly a primary right-sided bronchial carcinoma (65–80 per cent occurrence) or lymphoma? (SVC obstruction is also seen in metastatic breast, oesophageal and colorectal cancer.) Could they have extrinsic pressure, intraluminal thrombus or direct invasion of the vessel wall?
- Signs and symptoms
  - Early signs include facial, neck or limb swelling, tracheal or cerebral oedema, cough or dyspnoea, dysphagia, dizziness, syncope and/or chest pain.
  - Late signs include engorged neck and chest veins, tachypnea, plethora, upper extremity oedema, suffused injected conjunctivae, cyanosis.
  - Severe signs include headache worse on stooping, blurred vision, altered mental status, seizure, papilledema.
- Medical investigations and treatment may include relief of acute symptoms (opioids, benzodiazepines, steroids, diuresis), chest X-ray, MRI/CT, radiotherapy/chemotherapy, intravascular expandable metal stent or treatment of thrombosis.

Haemorrhage (internal or external)

- Does the patient have trauma, ulceration, inflammation or a growth that erodes through a blood vessel? Is the patient on anticoagulant therapy or taking other drugs that may cause bleeding?
- Does the patient have pain, bruising or swelling, dizziness, confusion, paler than normal skin, frank bleeding (nose, sputum, bowel and so on)?
- Medical investigations and treatment may include pressure dressings, investigations to identify the site and type of bleed, radiotherapy for bleeding skin metastasis and medication to reverse the cause.

Hypercalcaemia (> 3 mmol/L)

- Does the patient have multiple myeloma or breast cancer (40–50 per cent occurrence), leukaemia, lung, prostate or renal cell cancer?
- Signs and symptoms
  - Early signs include nausea and vomiting, lethargy, anorexia, thirst and polyuria.
  - Late signs include confusion and drowsiness, constipation, dehydration, non specific pain.
  - Eventually causes cardiac arrhythmias or coma.
- Medical investigations and treatment may include blood tests, reviewing with the patient and/or family whether or not to treat, hydration and diuresis or infusion/maintenance with bisphosphonates. Treatment can markedly improve symptoms even when a patient has advanced disease and limited life expectancy to make the end stages less traumatic for the patient and carers.

Seizures and acute confusion

- Does the patient have brain metastases, metabolic or toxic disturbances, vascular issues or an infection? What is their blood glucose level?
- Does the patient have emergency medications available such as diazepam, lorazepam or clonazepam?
- Medical investigations and treatment may include electrolyte and liver function blood tests, blood cultures, electrolyte replacement, phenytoin loading, phenobarbital, a review of medications, CT or LP.

Catastrophic bleed

- Does the patient have fungating tumours around major blood vessels, pelvic tumours (especially fistula into vagina or rectum), head and neck tumour(s) or a major bleeding disorder?
- Actions include: alerting the family/carer to the severity of the situation, providing support in person where possible, encouraging them to use catastrophic medications on hand (such as morphine or midazolam) or to call an ambulance if they are unable to administer the medication or do not have any in the home, advise them to use dark towels and bedding to absorb the blood that can then be discarded. Also advise the family/carer to not try to force the person to stay awake and to use extra blankets for warmth.

Pain/respiratory crises

- Is the patient at risk of a pathologic fracture, GI bleed, ischaemic or obstructed bowel, PE/clots or obstructed or collapsed lung? Are they acutely confused?
- Is the patient showing physical signs of hypoxia (severe breathlessness/inability to speak, blue/pale/grey, clammy, feeling of suffocation, copious sputum, decreased consciousness)?
- Medical investigations and treatment may include treatment of acute symptoms via medication/other clinical treatments, X-ray, CT, scopes or surgery.

Drug toxicity/side effects

- Respiratory depression caused by opioids or benzodiazepines can be reversed.
- Opioid toxicity can be treated by hydration and rotating opioids.
- Agitation can be managed with neuroleptics.
- Myoclonus can be managed with benzodiazepines.

Frequently asked questions

Caller dissatisfaction

'I am not happy with the options provided.'

'I just want you to send the nurse out for an injection.'

- *I'm sorry but the nurse is currently visiting someone else/located at* (name of location) *and cannot attend right away/will take a while to arrive.*
- *The nurses at* (name of service) *have advised me that you should first try taking the prescribed medication and 2/3 breakthroughs before a nurse can be sent out.*
- *The visiting nurse does not carry any medication with them and cannot prescribe medication. We need to organise a script from a doctor and/or to fill any scripts at a pharmacy, which may take a while.*
- *It would be neither kind nor helpful to offer choice where none really exists. All we can advise is what we think is best for you or* (the client) *and I think at the moment this is to (follow my instructions and assess the situation in another 30/60 minutes/call the GP/locum, call an ambulance and/or transfer* (the client) *to hospital).*
- *The comfort/health of you or* (the client) *is always our primary concern. We always aim to meet your wishes but sometimes there are limits to what can be done at home. Sometimes we have to decline requests because of* (these reasons/other).
- *Please tell me if you are not going to follow the agreed plan.*

Requesting hospice/hospital admission

'Should I take (the client) to hospital?'

'I want (the client) admitted to the hospice now.'

- *Can I just ask you a few questions before you call an ambulance?* Refer to nursing decision-making processes.
- *I would monitor the situation and watch for* (applicable symptoms)*. If you are still concerned in (x) hours call me back and we'll take it from there.*
- *If you go to the hospital you may have to wait a long time to be seen and admitted to a bed. It may be better to contact the GP/locum and wait for them to visit.*
- *Yes, I think you will need to go to the hospital. Can you take* (the client) *there yourself?*
- *I will hang up now. Ring 000 for an ambulance and I will call* (the hospital) *to let them know you will be coming in and why. Remember to take in all your current medications.*
- *Unfortunately I cannot directly arrange a hospice admission myself. I will need to contact* (palliative care service/the doctor) *to see if this is something we can arrange at short notice or whether you will have to wait until tomorrow.*
- *I will pass your request onto the day nurses tomorrow and see what can be arranged.*

Fatigue

'Why am I/is (the client) so tired?'

- *People with advancing illness often notice that they are very tired. This is often tiredness that is not relieved by sleep. It is rarely due to a single reversible factor* (such as anaemia).
- *Try to undertake a little manageable activity* (no matter how small) *as evidence suggests this will help your/their fatigue.*
- *Often, an increasing amount of time is spent sleeping, and (the dying person) may become uncommunicative, unresponsive and difficult to rouse. They may wish to be alone for periods of time.*
- *A lot of visitors can be overly stimulating and exhausting for a dying person. This may be an opportunity for you to take some time out and return later. Many families take turns sitting by the bedside to simply hold a hand, play gentle music, and quietly say final goodbyes.*

Anorexia

'Why do I keep losing weight?'
'Why don't/doesn't (the client) feel like eating?'
'Why has my/their taste for food changed?'
'What if (the client) stops eating?'

- Appetite tends to diminish as an illness *progresses.* The dying person often may want little or no food, taking sips of fluid only. This is a natural process, as the body is no longer able, or needing, to digest food.
- *Change in taste is common in advancing disease. Life-long favourite foods may no longer be of interest, and new favourites replace them.*
- *Weight loss is frequently encountered in advancing disease. Weight loss is not simply linked to your/their intake of food. It may be worsened by loss of appetite, but it is primarily due to a change to the body's metabolism. Increasing the number of kilojoules (calories) in the diet is unlikely to make a big difference.*
- *In the setting of advanced illness, weight loss, poor appetite and lack of energy are effects of the underlying condition, and are usually resistant to any treatment.*
- *Specifically in the dying process, there is a gradual reduction and eventual cessation of oral intake.*
- *Some dying people cannot eat because of problems swallowing food.*
- *The concept of a balanced diet should be set aside. As the goal is comfort,* (the client) *should be supported to eat* (only) *when and what they want. Trying to force a dying person to eat when they do not feel like it is likely to worsen any nausea or vomiting that is present.*
- *Advice from a dietician or speech therapist may be helpful and I can ask the palliative care nurses to put in a referral for you to those services.*
- *I know you feel helpless and concerned that* (the client) *is not eating. Eating is associated with health and so when the person does not eat their poor condition becomes more 'real'. Some people may eat simply to avoid upsetting their family even though it makes them feel worse. 'Food is love' is a commonly expressed sentiment, but you may need to learn other ways of expressing your love.*
- (The client) *may be unable to swallow and attempting to feed a dying person can cause considerable distress. When the mouth becomes very dry we use moist swabs, ice chips and lip balm to keep the mouth clean and comfortable.*

Hydration/alternative nutrition

'Does (the client) need intravenous fluids?'

'Why don't you at least put (him/her) on a drip?'

- *Your regular nurses and doctors need to make this decision and they will base it on a few different things including your wishes and on* (the client's) *condition.* (Good candidates include delirium/restlessness, renal impairment, symptomatic dry mouth/thirst, neuromuscular irritability and GIT obstruction.)

- *Medically administered nutrition and hydration is not routinely used when oral intake ceases. All treatments that are not required for comfort are stopped when a person is dying.*

- *If* (the client) *is settled and comfortable, it is unlikely that fluids will make them more comfortable. In the terminal stages of disease, there is a risk of fluids decreasing comfort.*

- *Fluids given subcutaneously may help if* (the client) *is dehydrated. If, however, the body is closing down, the need for fluids diminishes and even small amounts of fluids given may be more than can be tolerated.*

- *Thirst is not greatly influenced by medically administered fluids. Extra fluids can exacerbate things like fluid retention, making* (the client) *uncomfortable. If* (the client) *expresses they are thirsty keep the mouth moist at all times and try oral swabs, liquids or ice chips if they are alert and sitting bolt upright (if possible in the terminal phase).*

- (The client) *is not drinking because* (he/she) *is dying, not dying because* (he/she) *is not drinking.*

'Will nutritional supplements, nasogastric feeding, a percutaneous endoscopic gastrostomy (PEG) or total parenteral nutrition help?'

- *These interventions have not been found to improve quality of life or to prolong life, and may be likely to diminish quality of life.*

- *Risks with this treatment include agitation/discomfort/trauma, nausea/vomiting, aspiration pneumonia, increased secretions/cough, excessive urination, infection, CCF, cerebral oedema, metabolic disorder, effusion and ascites.*

- Clarification of the realities of the client's condition and their goals can help to alleviate distress.

Medication

'(The client) won't take (his/her) tablets. What should I do?'

- *You can crush the tablet and take it with food such as ice cream (if appropriate).*

- *Remind* (the client) *that if they don't take this mediation they may get bad pain, breathlessness, constipation, or nausea and vomiting.*

- *Is* (the client) *confused, unable to rouse/swallow or is there any other reason you can think of why they aren't taking the medication?*

- *Is the medication available in the house in any other form? Are you able to administer this?*

- *You can ask the doctor or pharmacist if the medication comes in an alternative form such as liquid, suppository or injection.*

- If the client wants to change medications, advise the client/carer to seek medical advice the next day.

'I think the wrong medication/dose has been taken. What should I do?'

- *Is* (the client) *conscious and breathing? Are you able to take their pulse rate?*

- *Do you know what they have taken and how much?*
- *I'm referring to my reference book/website and it says that the possible side effects of* (medication) *are…*
- *I will call your local nurse/doctor to discuss this with them and will call you back with suggestions as soon as I can.*
- *Just keep an eye on* (the client) *for the next* (period of time) *and watch for* (give suggestions). *If you are concerned call me back/call the locum/take* (the client) *to hospital.*
- *To minimise the chance of future mistakes consider asking your pharmacist for a dosette box. This is a box with compartments for each day. It enables someone to organise their week's medications all at one time. On a given day, the person opens that day's section of the box, and it's clear whether or not they have taken their medicine.*
- *To minimise the chance of future mistakes keep your medicines in their original containers and don't remove the labelling from those containers. Store medicines out of direct sunlight in a cool, dry place. Regularly clear out your medications and dispose of any medicine that is past its use-by date.*
- *Ask your chemist to package your medicines in childproof containers or keep medicines locked in cupboards out of reach. Ask for a list of dosage instructions that includes all the medications you are on (called a MediList).*

'I think (the client) has vomited up their medication. What should I do?'

- *How long after they took the tablet did they vomit?*
- *Could you see the tablet(s) in the vomit?*
- *Which tablets do you think they brought up?*
- *Have they now stopped vomiting? Are they nauseous?*
- *Use breakthrough medication until the next regular dose is due then recommence the usual regime.*
- *I will call your local nurse/doctor to discuss this with them and will call you back with suggestions as soon as I can.*

What are the common side effects of (medication)?'

- Refer to MIMS
- *Most pain medicines can have side effects. These are usually not serious and not everyone will get them. Sometimes they can be helped by treatment or by changing to a different drug.*
- *Your doctor should tell you what to look out for when taking any of these drugs, and what to do if you get side effects. If you are not sure about anything to do with your medications, talk to someone from your healthcare team/pharmacist.*
- *Ask your doctor as many questions as you need to about the medication* (the client) *is on. Writing them down as they come to mind may help.*
- *Side effects of a drug are quite common. The drug may upset the digestive system when swallowed, causing nausea or diarrhoea. Or, it may cause an allergic reaction. Sometimes, a drug may affect a part of the body other than the one it's intended for.*
- *Before a drug is allowed on the market, it is tested in clinical trials for quality, safety and effectiveness. By the time it is approved, the main side effects (if any) are usually known.*
- *If you have an adverse effect, don't take any more of the medicine but contact your doctor as soon as possible.*

- *Not everybody will get side effects from taking a drug. In some people they may be mild, in others more serious. Our genes have a big role in determining how we react to a particular drug – why some drugs works while others don't, and why some cause side effects and others don't.*

Opioids/analgesia

'Do I/they have to take opioids/morphine?'

- *You will always have the right to choose from the medications your doctor suggests you take. However, opioids/morphine usually provide the best relief of most pains and breathlessness. They are safe and predictable in their effect. Their dosage can be adjusted more precisely than almost any other pain reliever.*

'Will I/they become addicted to opioids/morphine?'

- *The risk of this is very rare, especially in people who have not used drugs in the past.*
- *People who take opioids/morphine for opioid-responsive pain do not become addicted to them. Only those who take opioids for reasons other than pain or breathlessness risk becoming addicted to them.*

'I want to save up until I have really bad pain – then I'll still have a strong painkiller to use.'

- *Controlling pain early reduces the likelihood of uncontrolled pain later. If pain is left uncontrolled for long periods of time, it becomes more and more difficult to control because the body responds to the pain by becoming 'rewired' to continue feeling the pain. Take your medication as prescribed. Dosages can always be adjusted over time.*

'Will the pain medications stop working if used too often?'

- *Pain medicine does not stop working. Sometimes the body gets used to a certain medication. This is called tolerance. Changing the dose or the medication itself often solves the problem.*

'I don't want to become a "zombie".'

- *For the first few days after starting opioids/morphine, and also after the dose has been increased, patients may notice some drowsiness, but this usually subsides rapidly. If drowsiness persists for a longer time it is important to review the dose or the effectiveness of the medication, and to consider trying a different opioid.*
- *Patients may sometimes notice a lack of concentration while taking opioids/morphine; however, unrelieved pain also causes this. When opioids/morphine are used in appropriate doses, patients are likely to be able to do more than they could previously while in pain.*

'If I am/they are taking opioids/morphine, does it mean I am/they are going to die soon?'

- *People often take opioids for long periods without death being close. Opioids may give an improved overall quality of life and allow an increased range of activities.*

'Can the pain medication make my/their heart stop or cause him/her to stop breathing?'
'Is the opioid/morphine going to hasten my/their death?'

- *Slowed respirations/heart events are rarely due to the effects of appropriately prescribed doses of opioids and are most often due to progressive disease and failing respiratory drive or heart age/disease.*
- *When prescribed in doses to control pain or breathlessness, opioids/morphine do not hasten death.*

'Why continue the analgesics now that he/she is unconscious?'

- *People who have had pain requiring regular analgesics should have these continued. People can experience pain when unconscious, so it is important to continue analgesics at the level that was needed when* (the client) *was fully awake and able to describe their pain. Continuing regular doses of analgesics in these circumstances does not hasten death. Loss of consciousness does not necessarily mean loss of hearing, or of awareness.*

Syringe driver/intima issues

'I think we need to start a syringe driver.'
'The syringe driver keeps beeping. How do I fix it?'
'I think the rate of the syringe driver needs to be increased.'
'The butterfly doesn't seem to be working/is causing (the client) pain.'

- Confirm type of syringe driver in use.
- Check for syringe driver orders from a medical officer.
- *I will contact the nurse on call to see if they will visit.*
- *I will get the nurse to visit to commence the syringe driver.*
- *Please contact the GP/locum for orders. They can contact the after-hours triage service with any queries as to dosages/rates.*
- *I can contact the palliative care specialist on call and get back to you.*
- *You will need to source the medication from the pharmacy before we can proceed.*
- *Check the insertion site. Is it hard, inflamed, hot to touch, itchy or leaking?*
- *Check for kinks in the tubing.*
- *Please turn off the machine and/or use breakthrough medications until tomorrow when we can contact the doctor/send out a nurse to assess* (the client) *and change the machine/tubing/ medication/rate if necessary.*

Confusion/refusing hospital

'(The client) is confused/restless. What is happening?'

- *There may be a muddled sense of time, place or person. This may fluctuate with moments of being perfectly lucid and oriented. Sometimes this is an adjustment to medications, but it is also about the dying person being in transition, physically and spiritually. It may help to identify yourself when you approach and to speak simply and clearly when you need to convey some information.*
- *Sometimes dying people see and talk to family members who have been deceased for some time. This may initially seem strange, but there is no need to be upset, or to deny the reality of the dying person's experience.*

'(The client) needs to go to hospital but is refusing to go. What should I do?'

- *Can I speak to* (the client) *to try to reassure them about the process?*
- *Tell* (the client) *that we can advise both the ambulance and the hospital about you which will speed up the process and get you seen as soon as possible.*
- *Do you want to try calling the locum service to see if there is a doctor who can visit the house?*
- *I will call your local nurse/doctor to discuss this with them and will call you back with suggestions as soon as I can.*

Depression

'What do I do if (the client) seems depressed?'

- *Do you think they are depressed or just sad at the moment?*
- *How long have the symptoms you've identified lasted (is it more than two weeks)?*
- *Is the person different from their usual self and they have lost interest in things that they used to enjoy?*
- *I will let the palliative care nurses know your concerns and they can make a referral to the psychologist or doctor for you.*
- *Try talking to* (the client) *about your concerns in a supportive, non-confrontational manner. Once you've raised your concerns give them a chance to talk and listen to what they have to say before offering them too many suggestions.*
- *You also need to look after yourself. Take some time out and talk to other people about the situation.*

Support services/complementary therapies

'What support services are available?'

- *The services available in your area can be explored with you by the palliative care team if you get in touch with them when they are next open. Refer to online resources where appropriate using the list in the resource folder.*

'What complementary/alternate therapies are available?'

- *The internet contains an overwhelming number of sites, the majority of which are developed by proponents of the therapies, and as such do not provide evidence-based information.*
- *Reliable information about alternative therapies can be obtained from the Cancer Council and the following websites:*
  - Palliative Care Victoria <www.pallcarevic.asn.au>
  - Palliative Care Australia <www.pallcare.org.au>
  - Care Search <www.caresearch.com.au>
  - Cancer Council Australia <http://www.cancer.org.au//aboutcancer/complementaryandalternativetherapies.htm>
  - ABC Consumer Guides: Using medicines safely <http://www.abc.net.au/health/consumerguides/stories/2004/09/02/1837198.htm>
  - National Prescribing Service <http://www.nps.org.au/research_and_evaluation/research/current_research/complementary_medicines/review_of_info_resources/comp_meds_info_summary>
  - American Cancer Society <http://www.cancer.org/docroot/ETO/content/ETO_5_3x_Guidelines_For_Using_Complementary_and_Alternative_Methods.asp>.

Equipment needs

'I need someone to access some pads/a bed pan/a hospital bed/other. Can you help?'
'My (equipment) is not working properly.'

- *You can access bed pans/pads/other from your pharmacy.*
- *Is it urgent that you have this equipment? If not please call back during business hours.*
- *The day nurses will need to organise access to equipment for you when they are next in. I will make a note of your request and ask them to call you.*
- *If you have the supplier's contact details please call them directly to find out when your equipment will be delivered.*

Dying process

'Is (the client) in pain/suffering?'
'What can I expect when my loved one is dying?'
'What should I expect to happen over the course of the illness?'

- It might be best to first enquire about any specific fear or fears.
- Describe how these problems would be managed to maintain comfort.
- *Whatever happens* (the client) *will be looked after and every effort will be made to keep them comfortable.*
- For most clients facing a predictable progressive incurable illness, the process of dying is one of the body progressively closing down. It is not marked by sudden changes in condition but by a gradual process.
- *Loss of energy, weight loss, drowsiness and increased or decreased temperature are frequently encountered and are the major manifestations of the body's winding down.*

'Will (the client) recover from this illness?'
'How long can I expect (the client) to live?'

- *It is really difficult to answer this question, especially over the phone. From what (the clients') notes say and what you've told me I think…* Be honest and refer them to their doctor if necessary.
- *May I enquire if there are any specific reasons why you may need to know (such as family travelling to visit)?*

'(The client) is breathing funny/having periods where they are not breathing.'
'Their breathing is slow/shallow/deep/intermittent.'

- *A change in breathing is significant. Breathing may become very shallow and rapid, or deep and slow, with slow spaces between breaths. Sometimes the breathing becomes quite 'rattly' due to an inability to cough up secretions. These signs are part of the normal process of dying due to disease affecting the drive to breathe.*
- *Breathing near the end of life is often characterised by pauses of many seconds, followed by a period of deep and rapid respiration. This may go on for a while. Respiratory drive will eventually diminish and respiration will eventually stop.*
- *I realise this breathing pattern can be extremely distressing but* (the client) *will be experiencing no distress from this and will be unaware of their breathing patterns.*

'Is (the client) dying?'
'Do you believe in God or heaven?'

- *There is no need to be afraid of death. Many people feel both relief and a profound sense of peace that the person they care about is finally at rest. People tend to die as they live, and simply 'being with' someone and allowing them to die their own death is a true sign of respect and dignity. Tears are a natural part of the grief process and saying goodbye. They do not need to be hidden, or apologised for; they are expressions of love.*
- *The final stage may be very draining. Although you may wish to be with the dying person as much as possible during this time, it is also important to take time out for some self-care. A nap, a warm bath, a coffee or a meal out may be enough to refresh you.*

Tips:

- Be open and honest.
- Tell them what is really important is what they believe.
- Often fear is the emotion behind this question. Fear of the unknown, fear of the physical event/process of death, emotional fear or fear of leaving people behind or being left behind, existential/spiritual doubts and/or fear of judgement.
- Ask if they would like to speak to a chaplain or clergy.
- Some people are quite resigned to dying, believing they are going to a better place and will see loved ones again, or that their time is over and this is the end.
- Be supportive of and respect their beliefs and concerns even if they are contradictory to your own.
- Always treat people with dignity in how you speak to them or assist them and in how you refer to them.

Family disagreement

'What do I do if family members disagree about treatment?'

- *It is best to speak with palliative care service about this when they are next open. They will most likely organise the social worker to help you all work through your issues.*
- *For now please try to focus on* (the client's) *best interests and try to get agreement about them and the goals of* (the client's) *care at the present time given their condition. Get everyone to speak openly about their opinions and feelings and brainstorm some solutions.*
- *If there is still disagreement you may need a mediated family meeting to help with the process.*

Death

'I think (the client) has died. What happens now?'

- *I'm sorry for your loss/my condolences/they are at peace now.*
- *Are you OK? Is there anyone with you or who you can call?*
- *Would you like a nurse to visit to help you through the steps you need to take (if applicable)?*
- *Can you position* (the client) *flat in bed with their arms straightened comfortably by the side? Would you like to bathe and dress the person in new pyjamas (the visiting nurse can help with this if required)?*
- *Have you chosen a funeral director? You can keep* (the client) *with you if you wish. When you are ready you can contact the funeral director who will arrange a time with you for removal.*
- *It's OK for you or other family to spend some time alone with* (the client) *if you need to.*
- *Do you want to talk about* (the client)*?*
- *It must be hard for you/it's a difficult time/it's OK to show your emotions.*

'Our GP is away and there is no covering locum. What should I do?'

- *The visiting nurse (or paramedic) can verify the death but this still needs to be certified by a doctor at a later stage.*

'I'm so sad because (the client) died alone.'

- *It's OK. It's common for people die when left alone.*
- *While we don't really know why, some people don't wish their relatives to witness their death.*

Sample templates

> **Disclaimer:** The Sample templates are guides only and may need to be adapted depending on the circumstances.

Admission to service – letter to GP

(Palliative care service letterhead)

(Date)

(GP/health service address)

Dear (GP's name),

Re: (client's name/date of birth)

This client has been admitted to the (name of service) palliative care service.

To assist us in delivering good symptom management, could you please provide this client with the following as required or PRN medications:

1 ....

2 ....

3 ....

The palliative care team is aware you may not have had contact with (client's name) recently. Working together in caring for this client, we will contact you as symptoms are assessed by our team and request orders for medications.

If you have any concerns or questions please do not hesitate to contact us.

Yours sincerely,

(Palliative care service contact details)

Discharge from service – letter to GP

(Palliative care service letterhead)

(Date)

(GP/health service address)

Dear (GP's name),

Re: (client's name/date of birth)

We are writing to confirm that (client's name) has been discharged from our palliative care service.

We have advised (client's name) that if their symptoms or medications change they should contact their local doctor.

If you would like to discuss this matter further please do not hesitate to contact us.

Yours sincerely,

(Palliative care service contact details)

Discharge from service – letter to client

(Palliative care service letterhead)

(Date)

(Client's address)

Dear (client's name),

Following our discussion we are writing to confirm that you have been discharged from our palliative care service.

If your symptoms or medications change, please contact your local doctor.

Yours sincerely,

(Palliative care service contact details)

End-of-life plan – for carers

(Palliative care service logo)

Directions if death occurs at home

These directions are for family and others (such as nurses, carers, doctors and police) to follow if death occurs at home, for this client.

(Carer's name)
(Carer's address)
(Carer's phone number)

This person is terminally ill and expected to die from chronic disease. It is possible that (he/she) will die at home. In the event of this occurring when the local doctor is available, family will make direct contact with (him/her).

(Doctor's name)
(Doctor's phone number)

In the event of this occurring when the local doctor is unavailable, family have been advised to:

1. Take the time they feel they need to, before calling anybody (but as a guide it is recommended that the appropriate notifications are made within a few hours of the deceased's death).

2. Phone the local police station on (phone number).

   A police officer will attend the home and arrange for removal of the body via the Government Undertaker.

3. The police officer will then notify the following general practitioner of the death in order to obtain a death certificate.

   Doctor (name): Surgery (phone number)
   After-hours: (phone number)

4. Once a death certificate has been issued, the family can then go ahead with funeral arrangements as desired using the undertaker of their choice.

NB: No funeral arrangements can be made until the death certificate has been provided to police.

(Palliative care service contact details)
Date (date)
c.c. (police station)

Guidelines for clients and carers

Date:……/………/………   Client ID:…………………………………

Some suggestions about what to do if you or your relative experience the following.

………………………………………(insert nature of incident)…………………………………………

The doctor has prescribed: (medication name)® (dosage)

Give: (medication name)® (dosage)

Give: (medication name)® (dosage)

If this does not work: Wait (time) and give (medication name) (dosage)

Further instructions:………………………………………………………………………………

Follow the symptom care advice on the back of this page (or insert)

If this does not work: Contact your local doctor during business hours

                or phone: (phone number)

Please note: (medication name)® (dosage) can be taken every

        (   ) hours **but no more than**   (   ) doses in 24 hours

---

………………………………………(**insert nature of incident**)..…………………………………..

The doctor has prescribed: (medication name)® (dosage)

Give: (medication name)® (dosage)

Give: (medication name)® (dosage)

If this does not work: Wait (time) and give (medication name)® (dosage)

Further instructions:………………………………………………………………………………

Follow the symptom care advice on the back of this page (or insert)

If this does not work: Contact your local doctor during business hours

                or phone: (phone number)

Please note: (medication name)® (dosage) can be taken every

        (   ) hours **but no more than**   (   ) doses in 24 hours

Symptom care advice for clients and carers

What to do if you or your relative experiences…

Agitation or anxiety

- Check that your relative is not too hot.
- Check the bedclothes for any irritation.
- Sit with them; take their hand and talk to them.
- If it's night time try a night light, radio or music.

Breathlessness

- Try increasing the air flow by a setting up a fan so it gently blows near the face, or by opening a window or door.
- If breathlessness is severe call an ambulance by ringing 000.

Constipation

Contact your doctor or nurse:

- At the next visit if there is no bowel movement for two days.
- If there is blood in or around anal or stool, there is no bowel movement within one day of taking a laxative or there is persistent cramps or vomiting.

Nausea or vomiting

- If vomiting: when vomiting stops rinse the mouth, clean the teeth and take small sips of water or suck ice cubes.
- Try regular sips of water with lemon juice or a piece of lemon, ginger ale or lemonade.
- Re-introduce foods slowly.

Pain

- Give pain medication early, rather than let the pain get severe.
- Keep a record of when pain medication is taken and show the doctor or nurse.

If prescribed regular medications for pain:

- Give/take this medication on time even if there is no pain at the time. This better controls the pain.
- If pain develops give/take the pain medication as suggested in this guideline.

Temperature

If you are having chemotherapy, please check your temperature morning and evening and any time if you feel hot, unwell or have the shakes (rigors).

Contact the chemotherapy staff if it is during the day – or if it is after-hours contact the after-hours service or attend an emergency department at a local hospital if:

- the body temperature is above 38° C for more than two hours or
- any of the following are experienced:

    * feeling unwell * dizziness * sweats * diarrhoea * pain on passing urine
    * a moist cough * rigors.

Do not delay in seeking medical help.

(continued…)

Symptom care advice for clients and carers (cont.)

Note: The purpose of this document is to provide advice for symptom management only, using medications that have already been prescribed to you or your relative by a doctor. This document contains suggestions for how to manage your or your relative's symptoms. It is not a prescription for medications. For complete medication information including side effects refer to the information that has been given from the prescribing doctor, pharmacist or hospital. This Guidelines for clients and carers does not replace that information.

Form completed by (print name):………………………… Signed: ………………………………

Designation: ……………………………… Date: ……/………/……… Time: ..……………………

Approval confirmed by:…………………………………………(name of prescribing doctor/GP)

Date: ……/………/……… Time: ……………………

Discussion with prescribing doctor included:

☐ Medications are current ☐ Dosage is as prescribed ☐ No interactions with other medications

Other:…………………………………………………………………………………………………

cc to:

Guidelines for patients and carers (Grampians and Loddon Mallee pilot project)

```
Community Patient with stable symptoms
    │ Yes ──→ PRN medications in the home dated and
    │         dispensed within 7 days
    │ No       OR
    ↓         Hospital discharge within 7 days and
  Requires urgent          pharmacy discharge list available
  medical review           │ Yes ──────────────────────────┐
    │ Yes    │ No          │ No                             │
    ↓        │             ↓                                │
  Arrange for │         Contact to GP/prescribing doctor.   │
  medical     │         Dr confirms medications prescribed. │
  review      │             │ No          │ Yes ────────────┤
              ↓             ↓             ↑                  │
  Contact to GP to notify   No ──→ Arrange for              │
  of patient condition and         medical and             │
  request medications to           medication review       │
  help in the management                                   │
  of symptoms.  Confirm      RN completes Guidelines for    │
  medications prescribed     Patients and Carers ←──────────┘
  at this stage.                   │
    │                              ↓
    ↓                       Confirmed with GP or
  RN completes Guidelines          prescribing doctor
  for Patients and Carers          (if available) by
  (including documenting Dr's       telephone or Doctor signature
  confirmation of medications).      │
    │                                ↓
    └──→ Guidelines for Patients and Carers
         given to patient/carer Copies sent to
         relevant health professionals ←─────────┘
```

After-hours service reporting template

After-hours telephone triage reporting template	
Date: / /	Time:
Client's name:	Caller:
Reason for call:	
Outcome:	
Comments:	
AH manager name:	
Fax number:	

After-hours contact list

Regional service	Address	Phone	Fax
xxx community palliative care service		03 xxxxxxxx	03 xxxxxxxx
xxx community palliative care service		03 xxxxxxxx	03 xxxxxxxx
xxx palliative care service		03 xxxxxxxx	03 xxxxxxxx
xxx inpatient, hospice, centre		03 xxxxxxxx	03 xxxxxxxx
xxx palliative care service		03 xxxxxxxx	03 xxxxxxxx
xxx palliative care service		03 xxxxxxxx	03 xxxxxxxx

Client resources

Client home held records

Client home held records are kept in the home and contain a variety of information on palliative care and the services supporting the client. Some are in the form of client diaries or a pocket sized pouch which is kept on the fridge and easily accessible by the local ambulance service.

Fridge magnet

A fridge magnet might also have provided the client to promote the after-hours telephone service.

Development and implementation of an after-hours rural (Grampians and Loddon Mallee pilot project)

PROJECT Snapshot
Palliative Care After Hours Project – Development and Implementation of an After Hours Rural Model in Grampians & Loddon Mallee Regions.

Situation
- DHS funded two projects (2009–2011) exploring different models of After Hours (AH) service delivery.
- Evaluation by Monash University.
- The Grampians and Loddon Mallee regions focussed on the development of a regional model.
- Previous research has identified a significant lack in consistent AH support in Palliative Care Services
- Anecdotal evidence suggests that some presentations to A&E could be avoided with an increase in carer and patient capacity to deal with predictable symptoms.
- Not all GP's give carer's prescriptions for pre-emptive medication.
- No consistent protocols across the regions with hospitals for access to medication exist.
- A regional AH model that addresses issues faced in rural and isolated areas is needed.
- The regional AH models is an expansion of the service delivery model developed by Wimmera Hospice care.
- Rural residents rarely access city based services and rarely use 'Nurse on call'.
- Geography, poor mobile phone coverage and low staff numbers in the regions creates significant safety issues for staff working after hours.

Priorities
1. To provide an accessible, sustainable and equitable after hours service for all community palliative care patients.
2. To develop standardized implementation and documentation to support patients and carers after hours.
3. To increase family and patient knowledge and capability to deal with predictable symptoms after hours.
4. To address staff safety issues for after hours in rural and remote areas.
5. To ensure full consultation and collaboration with all stakeholders.

Inputs
DHS –
- Funding
- Overview of project

Monash University –
- On-going evaluation of the project
- Establish base-line data

Advisory Group –
- Direction as needed

Reference Group –
- Three monthly meetings
- Statewide direction.

Grampians/Loddon Mallee Consortiums –
- Bi-monthly meetings
- Regional direction
- Direction and networking

Project Working Party –
- Regular meetings
- Direction and guidance
- Liaison with key personnel

Project Manager –
- Dvpt of project plans
- Delivery and implementation of project.

Other Service Providers to input local issues:
- Division of GP's
- Community Nursing/District
- Nursing services
- Acute care providers
- HACC agencies
- Ambulance Service Vic

Outputs

Activities
1. Discussions/survey of key stakeholders identifying gaps in current AH services.
2. Working Party established February 2010 – ongoing.
3. Research current and new telephone triage systems to best service the services.
4. Several triage nursing services developed to support the telephone system.
5. Education and support provided in the implementation of a consistent range of tools
   - PC clinical decision making charts for triage nurses.
   - Written care plans for patients & carers.
6. Protocols with hospitals and GP's developed to improve access to medications.
7. IT possibilities researched
8. On-going reports.
9. On-going evaluation.

Participation
1. Project Manager (PM); Key stakeholders; consumers in both regions; Monash
2. PM and stakeholders.
3. PM; Working Party; Grampians After Hours Service; Technical experts.
4. PM Working Party; Wimmera Hospice Care; Grampians AHS and others
5. PM; Working party; Wimmera Hospice; Learn PRN Training team; Consortia
6. PM; Working party; Division of GP; Consortia.
7. PM and technical experts
8. Project Manager
9. Monash; PM; Working Party

Outcomes

Short term
- Key personnel actively involved in the project and partnerships developed.
- Current models and procedures explored, analysed and enhanced.
- Consistent and effective templates and tools further developed.

Medium term
- Partnerships between the Consortia, hospitals and all involved in PC delivery strengthened.
- Families and patients empowered to deal with predictable symptoms after hours.
- A decrease in the number of home visits AH by Palliative care staff.
- Safety Issues for Nursing and medical staff after hours are greatly reduced.
- All services implement the *Guidelines for Patients and Carers*

Long term
- An accessible, cost effective and equitable AH Palliative care Regional Nursing telephone Triage Service.
- All patients and carers are well supported in all aspects of palliative care 24/7 all year round.
- Trips to AE afterhours are reduced.
- A greater awareness of Palliative Care Support among all medical personnel and the community.
- This AH Palliative Care model is implemented in other parts of Victoria.

Issues/Challenges
- Resistance to change at all levels of delivery by PC personnel.
- All community palliative care services are extremely 'time poor'.
- The challenges of a telephone system catering for CALD community members and the hearing impaired.
- Accessibility to medicines in regional areas after hours.
- Limited number of GP's in rural areas.
- Verification of death in isolated localities.
- Ensuring that the language on all templates and tools is easy to understand and in the carer's language.

Regional AH Service delivery MONTHLY Average Statistics (three Month average) 2009 & 2011

Service	Year	Patients	Description
0015 Service	2009	100 patients	PC staff AH roster – 52 AH PH calls; 25 AH home visits
0001 Service	2011	93 patients	PC staff AH roster – 37 AH PH calls; 15 AH home visits/Internal project worker implementing guidelines
0002 Service	2009	100 patients	PC nurses or DNS AH roster – 55 AH PH calls; 22 AH home visits
	2011	110 patients	PC nurses & DNS AH roster/located @ in-patient service w/onds – 13 AH PH calls; 2 AH home visits; 30 Guidelines
0003 Service	2009	22 patients	NO AH roster – Patients phone GP or hospital – No AH PH calls or visits
	2011	15 patients	AH telephone triage by Hospital AH managers – no calls/3 Guidelines written for patients and carers
0004 Service	2009	15 patients	PC staff AH roster – 2 AH PH calls; 1 AH home visit/Roster is very difficult to maintain
	2011	20 patients	AH telephone triage by Hospital AH managers – 3 calls; 0 visits/6 Guidelines written
0005 Service	2009	35 patients	NO AH roster – No calls or visits; AH support through local Hospital; Staffing issues
	2011	32 patients	AH telephone triage by Westvic After Hours Health Advice Service – 2 calls; 0 visits; 8 Guidelines written
0006 Service	2009	83 patients	NO roster – AH service provided by DNS
	2011	55 patients	AH telephone triage by Hospital AH managers – 6 calls; 0 visits; 8 Guidelines written
0007 Service	2009	40 patients	AH calls triaged by ward first, then referred to Outreach team – 10 AH PH calls; 3 home visits
	2011	45 patients	AH telephone triage support by CHAHMS – 4 AH PH calls; 1 home visit; 8 Guidelines written
0008 Service	2009	30 patients	NO AH roster – No calls or visits/Provide the Westvic AH number but no formal process for AH support
	2011	25 patients	AH telephone triage by Westvic After Hours Health Advice Service – No calls; 0 visits; 0 Guidelines
0009 Service	2009	68 patients	AH 24/7 service provided by Div1 PC and DN – 15 AH PH calls; 3 home visits
	2011	65 patients	AH telephone triage support by Westvic After Hours Health Advice Service – 4 calls; 1 visit; 30 Guidelines written
0010 Service	2009	52 patients	PC staff 24/7 roster – 27 AH PH calls; 17 visits
	2011	70 patients	AH telephone triage by Hospital AH managers – 6 AH PH calls; 2 visits; 10 Guidelines written
0011 Service	2009	26 patients	Supported by Westvic AH telephone triage service – no AH PH calls; 0 visits/Guidelines for majority of patients
	2011	31 patients	AH telephone triage support by Westvic After Hours Health Advice Service – 1 AH PH call; 0 visits; Guidelines for majority of patients.

Community palliative care after-hours regional service delivery model flow chart (Grampians and Loddon Mallee pilot project)

A strategic model of care that assists patients and carers to manage symptoms through written symptom management guidelines and after hours telephone triage support.

Education, Symptom management and Support Processes for Patients and Carers.

Guidelines on managing prescribed PRN medication in consultation with Palliative care (PC) Specialist; GP's and the PC Therapeutic Guidelines

Patient held record in Home Record Folders; Patient Diaries; Emergency Information Kits

Communication tool with local GP; Specialists; District Nurse; Hospital; Ambulance; Multi-disciplinary teams; After Hours (AH) Triage nurse; Visiting carers/family.

Link with PCOC and existing data gathering tools.

Link with service support through social workers; carer groups; bereavement support; workshops and volunteers.

Community Palliative Care Service Initiatives.

'Guidelines for Patients and Carers – What to do if…'

Clear, written instructions and education that enable patients and carers to manage symptoms after hours.

After Hours Palliative Care Nursing Telephone Triage Support Service

Option A: **Regional AH Nursing Telephone Triage Service Providers –** support several community palliative care services.

Option B: **Local Hospital AH managers –** support the local community palliative care service.

Option C: **Individual PC Services or District Nurses** provide AH telephone triage support to local community.

Optional AH Roster for Telephone Consult or Home Visit provision –
• Service specific and optional;
• Patient specific.

After Hours Nursing Telephone Triage Service:

Palliative Care Telephone Triage Protocols For Registered Nurses.

Implemented through:
• clinical telephone triage training
• processes
• policies and service agreements
• documentation
• authorised resource of the Julie K Briggs Nursing Telephone Triage Protocols.

Five Year Clinical Review through Wimmera Health Care Group

After Hours Service Delivery for Patients and Carers

Triage Nurse receives call from community palliative care patient/carer. Uses Palliative Care Telephone Protocols. (Patient information accessed through internal system or relayed verbally by caller using the Guidelines for Patients and Carers)

Call Ambulance/ Attend A & E/ Local Hospital

Seek medical care in the morning. RING back if concerned.

Follow home care advice. RING back if concerned.

Education, Symptom management and Support Processes for Patients and Carers.

Issue resolved

Issue unresolved

Further Assessment/ Triage required

On call GP (if available) OR **On Call PC Nurse** (if service has nominated on call roster) **Is contacted for a telephone consult or home visit.**

Call Ambulance/ Attend A & E/ Local Hospital

Hospital Discharge Planning (Includes)

Contact Report sent to PC service/District Nurse and GP

PC Service follows up next working day (weekend follow up may be by the district nurse)

Patient Assessment and Review of Guidelines for Patient and Carers

The Community Palliative Care After Hours Regional Service Delivery Model

A strategic model of care that assists patients and carers to manage symptoms through written symptom management guidelines and after hours telephone triage support.

Stage 1: Scope current situation of after-hours service delivery
• Structure of service • Current difficulties in after-hours service delivery • Current model of after-hours delivery • Statistics analysis • Current level of patient/carer education • Current level of patient/carer education • Current level of palliative care education and training for healthcare professionals • Service culture and practice • Communication protocols • IT capacity and issues • Change management
Stage 2: Development of the project action plan
• Engagement with internal stakeholders: identify internal champion • The Community Palliative Care After-Hours Regional Delivery Model elements
Stage 3: Implementation of element 1 – *The guidelines for patients and carers*
• Implementation of the project action plan • Communication protocols for promotion and feedback • IT support • Assessment and analysis • Further development
Stage 3: Development of the community palliative care after-hours telephone triage support service
• Engagement with stakeholders • Development of the project action plan • Communication protocols for information and feedback to all stakeholders • Implementation of the project action plan • Analysis and review
Stage 5: Implementation of the community palliative care after-hours service regional model

IT specifications for an after-hours service

Source: Loddon Mallee and Grampians pilot project final report to the Department of Health 2011

> **Disclaimer:** The IT specifications for an after-hours service are a guide only and may need to be adapted depending on the circumstances.

The key requirements for palliative care software systems are that they need to:

- ensure data security
- be available 24/7 and have support 24/7
- link in with existing client management systems, user interfaces and reports
- be simple to use
- perform quickly.

This document details an optimum dataset required within palliative care software systems to allow easy access and retrieval of client information by after-hours palliative care services. A sample web portal system is also described.

Optimum dataset

Data	Explanation
Client details	
Client's ID, Medicare number	
Client's name	Title, first name, surname, preferred name
Client's date of birth/age, sex	Date of birth, age in years, male/female
Client's home address	Facility name, unit, street number, street name, suburb, state, postcode
Client's current location	Where the client is currently located (such as home, inpatient acute hospital, inpatient palliative care unit, respite care, family/friend's home)
Alerts/cautions	Description of essential information regarding the client (such as two small dogs in backyard, code to medication box is…, history of family violence)
Client's telephone numbers	Home, mobile
Client's Indigenous status	Not Aboriginal or Torres Strait Islander, Aboriginal or Torres Strait Islander
Client's preferred language	English, interpreter required
Advance care plan, enduring power of attorney (medical), enduring power of attorney (financial)	ACP, MEPOA
Religion	
Occupation	
Carer details	
Carer's name	First name, surname
Carer's telephone numbers	Home, mobile, work
Carer's preferred language	English, interpreter required

Carer's relationship status	Partner, wife, husband, daughter, son, friend
Carer's location	Co-resident, non-resident
Carer's preferred language	English, interpreter required
Carer assessment	Availability, stress/distress, social support network, insight into diagnosis/prognosis, health status, respite, volunteer support, domestic care, Centrelink
GP and other health professionals	
General practitioner	Name, title, telephone number (BH, AH), fax, preferred involvement (total care, shared care), in GP absence (practice partners, deputising service, alternative phone)
Client's oncologist/specialist	List specialists
Other health professionals	Name, professional role, contact number (such as allied health, case managers)
Client assessment/information	
Diagnosis	Malignant/non-malignant with working diagnosis
Preferred site of death	Such as home, palliative care unit
Phase	Stable, unstable, deteriorating, terminal (PCOC)
Complexity	Low, medium, high
Medications	Current/ceased medications since time of first assessment by community palliative care (such as date, dose, route, frequency, PRN (Y/N), comments, emergency medication including if (a) drug is in place (b) current order)
Allergies	Adverse reactions to medications, foods
Edmonton chart	Charted scores for all relevant symptoms over time since admission to program
RUG-ADL score	
Last assessment/note	Last recorded assessment/note including recipient (client, carer, other), mode (face-to-face, telephone other), setting (home, telephone, other), purpose (follow up, monitor, evaluate, review), session (individual, family) Date recorded, who recorded the note and their designation
Notes record	All recorded notes regarding client/carer
Admissions	History of inpatient admissions
Care plan	
Client's community nursing round	
Other information	
Community nursing after-hours contact number	
Frequently used contact numbers	Develop a list of frequently used contact numbers (such as the local hospital)
On-call clinician's name, contact number	Develop roster for on-call such as: 1st on-call clinician: name, number 2nd on-call clinician: name, number

Sample web portal system

Portal login

The user logs into the after-hours portal using the details provided during registration. If the user is inactive within the portal for 30 minutes, they will automatically be logged out to prevent unauthorised access. When an attempt to log in is made, the portal system will record the following information (to allow for identification of any unauthorised login attempts and the location that they originated from):

- username
- date/time of login attempt
- IP address of user
- user agent (web browser) being used
- success/fail status.

Client search

The user can search for clients based on the following criteria:

- client's name
- age
- date of birth
- palliative care service
- underlying disease (diagnosis).

All dialog boxes will have predictive text input to allow for easy selection.

When the results are returned to the user, they will be presented in a table showing the following information:

- client's name
- client's address
- UR number
- date of birth
- palliative care service
- underlying disease.

The user can then select a client, and open their record.

Client information

When a client record is opened, an overview of their retrieved record is shown. The date and time that the record was opened will be stored for later use on the triage report. The following information will be displayed on a single screen (similar in design to that of the SCTT):

- client's name
- client's address and contact details
- allergies
- medications
- last three client notes
- last assessment
- alerts and risks.

The last three client notes will be displayed in summary (25 words), with the ability to expand and view the rest of the note by clicking a 'Read more' hyperlink.

After-hours palliative care triage report

Once the call has been resolved, the user is required to complete an after-hours palliative care triage report. This will be completed by clicking a link within the open client's record.

Fields such as the date, time and client name will automatically populate with the time that the client record was opened. The date and time values will be able to be modified by the user; however, the client name will be read-only.

The user will be given the option of previewing and/or printing the document in the same format as the triage reporting template.

When the user clicks on the button to 'Complete' the triage report, the triage data will be stored within the portal database. The system will then log the creation of the triage report, along with the community palliative care service, portal user name, date and time. The user will then be directed to the notifications screen.

Notifications

This screen will allow the user to send notifications to the designated recipient groups. These groups could include:

- the user recording the triage report
- the user's agency contacts (one or more)
- the community palliative care service the client is serviced by
- the district nursing service partnered with the community palliative care service.

The user will be able to select or deselect recipients from these groups. The user recording the triage report and the community palliative care service that the client is serviced by are mandatory for notifications.

Once the user is satisfied with the notification recipients, they can click the 'Send' button to dispatch the notifications.

Community palliative care service information

In order to improve the search capability for the after-hours nurses the following information is required:

- details relating to the community palliative care service
- SSL certificate for the community palliative care service
- list of known collaborations and partnerships
- palliative care services (inpatient, consultancy)
- palliative care partners
- users required to log in to the after-hours portal.

It is anticipated that callers may be under significant duress, and may not always know the name of the community palliative care service. By listing all known collaborations and partnerships at registration, the after-hours nurse will be able to search on any service providing palliative care assistance to the client.

User registration

Any users from the community palliative care service requiring access to the after-hours portal will require the following information stored in their user record:

- username (user's surname and first initial, for example, John Citizen = citizenj)
- password
- email address – for transmission of notifications
- security question and answer – used by the helpdesk/admin for verification when a password reset is required
- list of agencies the user provides service via.

By providing a list of agencies that the user provides service via, the portal system will be able to provide filtered options when the user is required to specify information such as the agency providing the service.

Data security

The after-hours portal is required to meet legislative requirements outlined under National E-Health Transition Authority (NEHTA) policies surrounding secure transmission of e-health records. For more information on the NEHTA policies see <http://www.nehta.gov.au/connecting-australia/secure-messaging>.

As the after-hours portal will be transmitting identifiable client information, all agencies registering to become a part of the after-hours portal will be required to have their own SSL certificate. Upon registration, the agency will provide the after-hours portal with a copy of their public key.

The after-hours portal will send all messages via the internet. As such, the after-hours portal will require a SSL certificate of its own. This method of encryption is known as 'transport layer security'. The use of SSL certificates in conjunction with WS-Security will provide end-to-end security, ensuring data confidentiality and integrity when transmitted.

SSL certificates for the agencies registered with the after-hours portal are not required to be purchased from a certificate authority, and can be generated at request.

Calls by client report

A statistical report will be developed for the portal system in order to show all calls meeting a set of criteria, grouped by client. The available filtering criteria will be as follows:

- client
- start date and end date
- palliative care service
- triage nurse
- call outcome.

Calls by outcome report

A statistical report will be developed for the portal system in order to show all calls meeting a set of criteria, grouped by call outcome. The available filtering criteria will be as follows:

- client
- start date and end date
- palliative care service
- triage nurse
- call outcome.

Remote interface

As the after-hours portal is required to pull information from various agencies, all registered agencies will need to ensure their client management system follows one of the following methodologies:

- View-based approach – this approach is the least work for a software vendor to implement. It comprises a set of database views that provide the information required for the after-hours portal. These views will then be accessed via a SOAP Connector at the agency, which can be polled by the after-hours portal at request.
  - the SOAP connector will make use of SSL and the WS-Security toolkits to receive requests from the portal. Once a request has been received, the request is processed by the connector and encrypted, before being returned to the after-hours portal. The SOAP Connector will require a port be accessible externally by the after-hours portal. The port number forwarded is at the discretion of the registered agencies' IT infrastructure manager. The port number to be used is submitted at the time of registration with the after-hours portal. The SOAP connector returns data in an XML format.
- Inbuilt SOAP connector – this approach functions the same as the View-based approach however instead of being an external component, the Inbuilt SOAP Connector is built into the client Management System connecting the AH Portal. This method gives the Client Management System more control over access to their database structure; however places significant development overheads on them.

Literature review

> **Disclaimer:** The *Literature review* is a summary of relevant literature in the area of after-hours palliative care but does not constitute legal advice nor necessarily reflect the views of the Department of Health.

Palliative care service delivery has evolved from single discipline end-of-life care in institutions to incorporate supportive and holistic inpatient and community-based interdisciplinary home-based services, with specialist knowledge of symptom control (Tan et al. 2009; Watters 1997). The aim of community services is to enable patients to live at home for as long as possible where this is their preference (Aranda and Hayman-White 2001), achieve quality of life and alleviate workforce issues facing other acute and non-acute specialties (Carr and Hall, Medicine 20 Congress Toronto (M20CT) 2009). These aims are of growing importance given the projected Australian figures of people requiring end-of-life care due to chronic or malignant disease into the future are predicted to exceed the number of available carers (70 per cent will live with chronic disease with a 40–50 per cent increase in cancers by 2021) (Aleksandric and Hanson for Palliative Care Australia (PCA) 2010).

A hundred years ago people were dying young, at home, from a short acute illness and cared for by their family and community, whereas today people are dying older, in institutionalised care and as a consequence of chronic illness, cancer and/or frailty/dementia with fewer familial or community supports available (Aleksandric and Hanson for PCA 2010; Devlin and McIlfatrick 2010; O'Connor et al. for PCA 2009).

Approximately three-quarters of deaths in Australia in 2008 could have been anticipated (Aleksandric and Hanson for PCA 2010; O'Connor et al. for PCA 2009; Murray et al. 2010) with 50 per cent having a diagnosis that would have benefited from palliative care intervention. Where interdisciplinary community palliative care services are involved people are more likely to die in their usual place of residence (Houttekier et al. 2010). There are also associated benefits for the client and family including: improved client choice of care setting; minimised disruption to routines; preserved family autonomy (Funk et al. 2010); reduced need to travel to and from inpatient units; fewer hospital admissions; lessened feelings of powerlessness and fear and increased feelings of control related to their illness; better maintained functional ability (such as due to decreased client exhaustion from travel); increased dignity; and increased physical/psychological comfort (Houttekier et al. 2010) for those who can remain at home.

Although the emergency inpatient setting may be the best location of care in some circumstances, a reduced number of emergency department visits is often cited as an indicator of quality of end-of-life care and an indication that the carer is well prepared and coping with the demands of their role (Elliker and Barnes 2008; Lawson et al. 2009). Visits to emergency departments for palliative care clients can be highly stressful due to the busy environment and curative focus of clinicians, and these visits are often unwanted (O'Connor et al. for PCA 2009).

The hospital often has little information about the client and cannot provide the privacy and support required by the client and their family (Lawson et al. 2009). Community palliative care services that include a responsive after-hours service designed around client needs have been associated with reduced emergency department visits (Lawson et al. 2009).

After-hours support

Feelings of distress, uncertainty, isolation and anxiety can be magnified after hours when services are less accessible (Phillips et al. 2008; Payne 2010a). Regardless of how well community palliative care services assess and anticipate client and family/carer needs, real or perceived crises including difficult to manage symptoms will still occur and therefore access to information, assistance and support 24 hours a day is critical (Phillips et al. 2008; Yardley et al. 2009).

Developing after-hours support that is appropriate, accessible, effective and able to maintain continuity of care regardless of client location has been incorporated into many health policies both in Australia and overseas in the past 10–20 years (Department of Health and Ageing (DoHA) 2010; Phillips et al. 2008; Yardley et al. 2009). After-hours support for community palliative care clients can vary depending on local resources and preferences. Services can include telephone support to planned or unplanned home visits and specialist liaison for GPs, hospitals, generalist or specialist district/community nurses or palliative care/hospice nurses (Phillips et al. 2008; Hardwick, Cancer Institute New South Wales (CINSW) 2009; Yardley et al. 2009).

Best practice care planning

Raftery and Willard (2010) state that individuals should be able to craft what it means to them to have a 'good death', therefore care planning is a tool that when used properly can improve client quality of life, satisfaction and overall acceptance of death. They state that a lack of client preparation may result in death away from the place of choice or poorly controlled symptoms and associated suffering. They also state that clients can take as much or as little responsibility as they want in administering treatments and that care plans should be used as a professional communication tool regarding progress and decisions around client care (Raferty and Willard 2010).

Payne (2010a) states that care plans for community palliative care clients should focus on crisis prevention rather than crisis reaction, while Smith and Porock (2009) see care planning as continuous anticipation and pre-planning for all possible outcomes involving client communication of preferences for care. Skinner (2001) places the responsibility of care planning on the case manager/key worker; within the community palliative care services setting this is often the specialist nurse (Quinn and Lawrie 2010).

Heyland et al. (2010) and Stajduhar et al. (2010) cite findings that the needs of many carers remain unmet suggesting usual approaches may be insufficient, particularly assessment and treatment of psychological issues such as anxiety and depression. Skinner (2001) feels carer preparation regarding potential symptoms/emergency scenarios and their management should be part of client care planning. Hudson et al. (2004) also recommend that carers' needs are addressed in client care plans. While Thomas et al. (2010) found that only some services included carer content in their client care plans and suggested separate carer plans. Hudson et al. (2004) also suggest carer plans should cover what information they require, how this is to be delivered, what assistance is still required, when and how this is to be addressed and by whom (decided at interdisciplinary team meetings).

Wittenberg-Lyles et al. (2010) found that carers should be involved in care planning for the client. They looked at the differences between interdisciplinary care planning/case conferencing with and without carer involvement. Where the carer was involved the meetings resulted in five times higher client-centred goals, increased discussion of bio-psychosocial problems versus behavioural/functional problems and double the amount of interdisciplinary interventions. The discussions per client were also longer (almost eight minutes compared with three minutes 20 seconds).

Advance care planning

Advance care planning is based on the common law right of individuals to make decisions about their medical treatment including the right for a competent person to refuse treatment (O'Connor et al. for PCA 2009). Within the palliative care setting, advance care plans are seen to be an important tool in providing client choice regarding active medical treatment if their condition is irretrievable (O'Connor et al. for PCA 2009) and provide the opportunity to avoid distressing experiences at the end of their life (DoHA 2010). Many hospital complaints are about care around the time of death (Thompson-Hill et al. 2009). O'Connor et al. (for PCA 2009) report that distressed family members and a client who is too exhausted and breathless to speak, are not good sources of informed consent.

Advance care planning has been linked to increased client and family satisfaction with care, improved adherence to the client's wishes, fewer hospitalisations and less resource use in nursing homes, fewer life-sustaining procedures, and lower rates of intensive care unit admissions and, for advanced cancer patients, substantially lower healthcare costs in the final week of life (Vogel 2011). The documents are more likely to be completed if a client is assisted by a healthcare provider (DoHA 2010). Advance care plans can also assist families by providing timely information about a client's condition, prognosis and preference for end-of-life care (including any unwanted support measures/technology); this information being the preference for families in a study cited by Heyland et al. (2010). The key is that the document is available, read and understood by all client stakeholders as conflict between family members and healthcare providers can compromise the effectiveness of the plan (Goodridge and Duggleby 2010).

However, the implementation of advance care plans is currently facing many barriers. Many individuals do not receive information about advance care planning from their health services and, when they do, it may be hampered by poor communication between the healthcare provider and the client, with a mismatch between what the client wants to discuss and what is actually discussed (DoHA 2010). Healthcare providers have reported that initiating discussions about end-of-life care are often time consuming, that they have concerns about the level of care available locally to support client wishes and that end-of-life discussions can generate a significant aftermath of client and carer needs (Thompson-Hill et al. 2009). In addition, Hebert et al. (2009) found that healthcare providers often feel they have inadequate expertise in discussing end-of-life issues. Thompson-Hill et al. (2009) suggested healthcare providers may need advanced communications training to overcome some of these perceived difficulties.

Medically instigated interventions are not always in line with client wishes (due to a lack of client health literacy and the use of medical jargon), particularly if the document is presented in an acute setting during a crisis situation. O'Connor et al. (for PCA 2009) state that advance care plans are harder to prepare and more difficult to have enacted than expected. They suggest that acute doctors currently being presented with an advance care plan would be fearful for their professional reputation if they were seeing the client for the first time, especially if out of hours when senior doctors are not available.

The federal Department of Health and Ageing (2010) and O'Connor et al. (for PCA 2009) outline the current recommendations for advance care plans to be nationally consistent and governed by the Attorney-General (similar to the framework currently under development by the Canadian Hospice Palliative Care Association (Vogel 2011)), as well as a national information campaign for healthcare providers and the general community (funded by the government) to raise awareness about the need for and benefits of advance care plans.

The role of GPs

Many community palliative care services rely on the client's GP to provide the majority of care with their direct or indirect support (O'Connor et al. for PCA 2009; Mulvihill et al. 2010). Glover et al. (for PCV 2009) state that GPs (and other primary care team members) are crucial in coordinated end-of-life care. Aleksandric and Hanson (for PCA 2010) state that GP-led care reduces the frequency of end-of-life client hospital admissions and improves quality of life. Houttekier et al. (2010) and Mulvihill et al. (2010) found that dying at home occurs more often if the client's GP is involved in care during the last three months of life but also if client preferences are explored and palliative care services are involved in meeting them. However, only 15 per cent of GPs were found by Tan et al. (2009) to have undertaken postgraduate palliative care training due to lack of time or availability of suitable courses (six per cent higher than a similar study in Sydney). They also found that GPs not involved in providing palliative care were likely to be younger with less experience; this creates implications for the future when the current ageing GP workforce retire (Tan et al. 2009).

Few client deaths under the care of a GP are totally unexpected (Murray et al. 2010); however, an Australian GP will only care for a median of five to six terminally ill people per year (Mulvihill et al. 2010). O'Connor et al. (for PCA 2009) puts the figure at one to two per year. This makes it difficult for GPs to get expertise in terminal pain treatment or to seek out palliative care education. These issues, alongside a system of medical and surgical specialist doctor referral for those with complex conditions, can result in GP deskilling in end-of-life care (O'Connor et al. for PCA 2009). Problems regarding care planning for symptom management can occur when GPs do not prescribe suitable palliative care medications for clients, or only prescribe oral breakthrough medication, even if injectables are directly requested by specialist nurses (Ciechomski et al. 2009; Wellman 2007).

As there is a shortage of palliative care medical specialists across service areas, community palliative care services need collaborative and innovative approaches in engaging GPs in client care (O'Connor et al. for PCA 2009) and palliative care upskilling. Mulvihill et al. (2010) state that palliative care specialists and community generalists must find a common language, clarify their roles and establish a non-hierarchical relationship that is respectful and committed, be it face to face or using other communication channels. O'Connor et al. (for PCA 2009) suggest GPs be involved in interdisciplinary team meetings; this could help avoid clients getting conflicting information about managing their illness (Goodridge and Duggleby 2010). Many GPs are not aware that time spent on this can be claimed under the Australian Enhanced Primary Care Medicare Item for care planning (Tan et al. 2009).

Medication and pain management

Clients, especially those with pain, need rescue medications that provide appropriately fast onset (Science Blog 2011). O'Connor et al. (for PCA 2009) state that 30–50 per cent of clients experience pain that is under-treated at end-of-life, leading to a significant reduction in quality of life for clients and families. Poor symptom control is a major fear of palliative clients and can lead to the choice of a hospital admission over home care, especially for complex conditions (Wowch et al. 2009). Goodridge and Duggleby (2010) state that providers lacking specialised knowledge regarding appropriate palliative prescribing can jeopardise client safety. This can include GP prescribing and poorly executed hospital discharges/outpatient prescribing.

Within the general and medical communities there still exists a level of opioid phobia stemming from incorrect knowledge and attitudes to pain management (O'Connor et al. for PCA 2009). In addition, some pain medications and other drugs commonly used for symptom management in palliative care are not universally accessible through PBS and/or local pharmacies (Aleksandric and Hanson for PCA 2010; O'Connor et al. for PCA 2009). Patient access to Schedule 8 breakthrough medications in low-level care facilities that are not staffed with registered or medication enrolled nurses is also problematic (O'Connor et al. for PCA 2009).

Currently, some local services create 'workaround' strategies to overcome medication access issues, but these are ad hoc (Aleksandric and Hanson for PCA 2010); O'Connor et al. for PCA 2009; Wellman 2007). In the future community palliative care services may have the ability to overcome inadequate palliative prescribing via an increased use of community pharmacists for client/carer education and GP liaison (Ise et al. 2010) or nurse practitioners, as currently undertaken by palliative care clinical nurse specialists in the United Kingdom (Quinn and Lawrie 2010).

It must be acknowledged that clients and their carers may also take responsibility for this under treatment due to their own beliefs about strong medication and opioids (Borneman et al. 2010), their social circumstances being unsuitable for in home supply of palliative medications (Wellman 2007) or client refusal to comply with the prescribed medication regime (Raferty and Willard 2010; Science Blog 2011). Sourcing palliative medications can sometimes be problematic and appropriate medication prescription can be effected by late referral of clients in the terminal phase.

Client information systems

The confidential sharing of electronic client information between relevant service providers is considered the gold standard in community and after-hours palliative care service provision. Providing after-hours access to client information allows for improved continuity, quality and timeliness of palliative care (Yardley et al. 2009; Carr and Hall, M20CT 2009). Electronic client records allow improved consistency of practice, safety and continuity of care by ensuring the right information is handed over (Thick 2010). This is of high importance given that after-hours services have the responsibility for care of clients 128 hours out of 168 hours a week (where the community palliative care services operates business hours Monday to Friday only) (Skinner 2001).

Essential client information enables nurses to more effectively address the client issues that arise after hours (Skinner 2001). Brumley et al. (2006) state that improved access to client information allows triage nurses to feel more confident in assessing and assisting clients after hours and leads to better client outcomes, including improved ability to negotiate care options with callers, on-call nurses and doctors. This way the common problems associated with after-hours palliative care provision can be avoided (such as clients needing to repeat information, excess referral calls, medication errors or other adverse events), particularly when after-hours staff don't know the caller or if medical decisions need to be made (Brumley et al. 2006; Mulvihill et al. 2010).

Access to electronic client end-of-life care preferences and plans has the potential to be very valuable for primary and tertiary care after hours, including for ambulance services (Thompson-Hill et al. 2009). O'Connor et al. (for PCA 2009) state that advance care plans included on e-records is an exciting possibility.

Information technology including e-health is one of the five key building blocks for the Australian *National primary health care strategy* (DoHA 2010); however, electronic client information systems are still difficult to implement, maintain and manage (Yardley et al. 2009). O'Connor et al. (for PCA 2009) state that a health service's ability to meet client needs and provide holistic, collaborative and interdisciplinary care is hampered by inadequate health IT infrastructure, leading to problems in sharing client information with other healthcare providers, gaps and duplication in care and restricted options for care in a client's place of choice. Thick (2010) supports this view by stating that paper records are not fit for purpose for much longer. Client-held paper-based records can assist in solving some of these problems where difficulties implementing an electronic client information system exist (Brumley et al. 2006). The scope of the after-hours role also needs to be clearly defined where staff are unable to access clinical records to mitigate risk (Phillips et al. 2008).

Brumley et al. (2006) tested a single page of key regional client information, updated as necessary on computer and shared electronically with the after-hours service and also the client's GP (in the unstable/latter phases of care). They found that after-hours services require information on all community palliative care clients (as it is difficult to predict after-hours requirements for unstable clients), that electronic client information must be accurate, reliable, well presented and up to date, and that electronic client information enables triage staff to provide more rapid responses for clients by avoiding the need for them to find the information in folders of paper-based information. Brumley et al. (2006) also found that community palliative care services could not predict which clients would utilise an after-hours service.

In addition, Tan et al. (2009) recommend that client information should be concise, relevant, timely and accessible by nurses and doctors involved in after-hours support. Quinn and Lawrie (2010) recommend that shared client information, especially about medications, needs to be updated as soon as possible, preferably on the same working day but not exceeding 48 hours. They also recommend any business hours or after-hours documentation is an accurate record of assessment and care provided, unambiguous and in line with guidelines. Carr and Hall (M2OCT 2009) support the inclusion of the Edmonton Symptom Assessment System (ESAS) and/or other symptom scores.

In terms of functional success factors, Carr and Hall (M2OCT 2009) present five key factors for electronic client information systems; however, they note that integrated systems are challenging and costly to implement, with varying degree of service readiness:

- multiple means of access – securely over the internet
- ease of use – expert design of interfaces, simple, uncluttered, appealing colours and graphics, clear 'what to do next', positive feedback on clicking, histogram
- central hosting – economy of scale (hardware, support, account management, security and privacy), sharing of client data between hospitals, email alert behaviours
- integration (access from hospital portals).

After-hours telephone triage

Healthcare providers have offered telephone triage programs since the early 1970s with the aim of facilitating healthcare access and 'the right level of care from the right provider at the right time' (Wheeler and Siebelt 1997). Taubert and Nelson (2010) state that patients with cancer spend 90 per cent of their last year of life in their home and at least two-thirds of this falls within out-of-hours time.

Worth et al. (2006) conducted research with community palliative care clients and carers in the United Kingdom to establish their perceptions about using after-hours services, including any barriers to use. They found that clients and carers were hesitant to use these services if they had certain variations of personality or help seeking behaviours or if they:

- were anxious/embarrassed about the legitimacy/urgency of their problem (preferring to 'wait until the morning')
- were fearful of being labelled demanding or difficult
- were fearful of being advised to go to hospital by someone who didn't know them
- had a previous negative experience with the service or had low expectations of it
- did not know who to call
- perceived the process as challenging (unknown person at the end of the line, inability to give a clear account of their problem/needs, lack of regional nursing support)
- were just wanting a visit and did not want to answer the triage questions or attend a primary healthcare facility (in some cases due to feeling in equipped to answer them).

They found that the opposite of these barriers encouraged individuals to use an after-hours support service including:

- learning how to manage the system
- previous positive experience(s) with the service/perceived effective triaging (including addressing carer needs for support)
- clear, accessible information about the service, contact information and encouragement to use the service
- staff with good communication skills
- staff who are known to the individual
- early referral to the service
- ensuring appropriate medications were available.

Services provided by a contracted service or from a centralised location may be perceived negatively or as a barrier to use by some clients (Fatovich et al. 1998); however, the availability of client/carer education, home visiting and good communication between business hours and after-hours services, particularly regarding up-to-date client information, can address concerns about continuity of care and create successful interactions (Worth et al. 2006).

Australian research suggests that after-hours community palliative care services based around centralised telephone triaging is increasingly being recognised as a strategy to: provide equitable access for clients, carers and healthcare providers; promote self-management; address geographic service restrictions; and relieve pressure on the ambulance service and hospital emergency departments (Phillips et al. 2008). The role of telephone triage has been found to include symptom assessment, home treatment advice, referral, information brokering and crisis intervention (Phillips et al. 2008). Telephone triage is seen to provide accessible, safe and inexpensive after-hours needs-based support that maximises available human resources (Hahne et al. WMC/WHCG 2011).

Palliative care telephone triage can be considerably more complex than the provision of general healthcare advice and referral (Wellman 2007). Worth et al. (2006) state that palliative care needs are not predictable, that telephone triage calls can be variable and infrequent but that some can prove time consuming and personally demanding. To enhance safety and effectiveness, Watters (1997) recommends that an after-hours service should be provided by hospice and/or specialist palliative care nursing staff (defined as having specialist knowledge, qualifications and/or experience in oncology or palliative care). Yardley et al. (2009) also recommends that community palliative care after-hours services are provided by senior hospice nurses with on-call medical support and help available from an appropriate colleague. Finally Carlebach and Shucksmith (2010) found that telephone triage by experienced palliative care staff resulted in callers finding the operators provided more adequate emotional support, were more understanding of their situation, did not rush the caller and were able to resolve immediate clinical problems or arrange rapid emergency response.

Local and/or generalist after-hours services provided by emergency departments, district nurses or GPs can add extra burden to already time-poor staff (Tan et al. 2009) and may be unable to meet the complex needs associated with palliative and end-of-life care (Phillips et al. 2008). Tan et al. (2009) found that GPs, clients, carers and nurses want competent and qualified palliative care nurses on after-hours services and suggested that referral and type of follow-up of after-hours calls related to nurse training and confidence in palliative care (Tan et al. 2009).

Yardley et al. (2009) found that specialist after-hours services are required for efficient and appropriate care, stating that it is important that advice given is of high quality and delivered by appropriately qualified practitioners. O'Connor et al. (for PCA 2009) raised the concern that a lack of knowledge or confidence at a critical point could lead to error and suggested the use of experienced staff to provide after-hours services should be mandatory.

Phillips et al. (2008) presented a summary of research conducted in Australia and the United Kingdom into existing after-hours services for community palliative care clients. Many studies described had very low numbers of calls. Some telephone triage services were provided by on-call doctors for clients and carers or by senior nursing or medical staff for primary care teams only (GPs and community nurses). In addition Payne (2010a) presented a unique night telephone service that was able to provide respite carers, crises contact numbers, access to drugs and equipment and 24-hour district nursing support. Carlebach and Shucksmith (2010) presented a hospice-based incoming (triage) and outgoing (proactive support) telephone service backed up by specialist palliative care nurse visits.

Reasons for contacting an after-hours service

Aranda and Hayman-White (2001), Worth et al. (2006) and Yardley et al. (2009) found that the reasons palliative care clients contacted an after-hours service were for advice about managing physical symptoms (especially pain), psychological support, general information on services and reassurance if anxious or about medication usage. Aranda and Hayman-White (2001) found that after-hours home visits were not predicted by call reason, living arrangements, diagnosis or clinical problems, but could be predicted by the client being close to death or having died.

Policies, guidelines and service models

To date there has been minimal evidence collected to guide development and implementation of optimal and efficient methods of after-hours community palliative care services provision (Phillips et al. 2008; Hahne et al. WMC/WHCG 2011). The existing evidence suggests the optimal model is one that provides accessible, confidential, simple and convenient telephone access, via a single point of contact, that provides reliable nursing advice in the absence of competing priorities and allows for appropriate and efficient care delivery and referral for both metropolitan and rural community palliative care services users (Phillips et al. 2008; Worth et al. 2006; Wilkes et al. 2004). Calls may be straightforward or protracted and complex, especially where clients are in the terminal stages, hence dedicated staff are needed (Elliker and Barnes 2008).

Phillips et al. (2008) state that after-hours staff make important decisions, often under conditions of uncertainty and urgency and that services should aim to provide a standardised quality of service to avoid inappropriate advice being provided and the associated medico-legal risks. They also say that it is possible services could be held accountable for poor advice or refusal to help and that once advice is offered over the phone, the staff member has assumed legal obligation to the caller and is responsible for the advice given. Phillips et al. (2008) also found that district nurses and doctors had increased confidence that potential after-hours risks could be minimised via the use of policies and clinical decision making protocols.

With this in mind, clearly defined scope of practice, as well as protocols and guidelines addressing nursing assessment, nursing diagnosis, treatment advice and referral, have been found to be effective in assisting telephone triage staff in providing consistent and efficient support for clients (Wellman 2007, Wheeler and Siebelt 1997), as well as gathering essential call data, facilitating issue management and completing written documentation (Phillips et al. 2008; Fatovich 1998, Hahne et al. WMC/WHCG 2011); however, most services rely on the inherent and autonomous aspect of telephone triage residing the nursing experience and knowledge of staff (Wellman 2007).

Wellman (2007) outlined that formal after-hours guidelines should include:

- how to proceed with the different technologies used by each agency
- procedures to follow if further actions are required
- how to escalate important calls
- formal assessment protocols to evaluate client needs
- question prompts and algorithms to minimise missing vital client information.

Yardley et al. (2009) and Elliker and Barnes (2008) found that an after-hours service requires:

- systematic design and specifications
- agreed service contracts
- a dedicated telephone number and office
- prioritisation of calls and expected response times
- adequate time, resources and administrative support
- a call record form (caller name and phone number, time and length of call, type of caller, reason for call, advice given, if GP or nurse called out)
- formal clinical governance procedures (including quality and cost auditing, regular review of calls by senior medical, pharmacy and management staff, personal appraisal and management feedback to staff)

- ongoing audit of standards and training of staff
- a system to guide responses to requests
- a local policy for advice on symptom control
- the ability to make referral calls for clients where needed
- satisfaction questionnaires sent out to first-time callers.

The Australian Medical Association (AMA) recommends in their 2004 position statement on call centre triage and advice services (2004b) their considerations for call centre models.

Staff education

Phillips et al. (2008) found that organisations operating a telephone triage service need to provide the relevant staff with ongoing education, support and guidelines as telephone triage is a difficult skill. Health assessment over the phone varies significantly from face–to-face assessment in that operators are not able to perform a physical assessment or assess body language cues. Instead they have to rely on verbal descriptions of symptoms from the caller (Elliker and Barnes 2008).

Although telephone triage uses the existing skills set of experienced nurses in symptom management and problem solving and knowledge of community-based care (Phillips et al. 2008) staff need to be supported in maintaining and enhancing this knowledge over time. Brajtman et al. (2009) state that the development of competency is a valued goal for all nurses and that meaningful and empowering learning experiences give nurses experience as knowledge users, critical thinkers, decision-makers, inter-professional collaborators and active participants in the delivery of optimal client and family end-of-life care. They found that the content of nursing education should include:

- staff descriptions of a clinical situation encountered and exploration of the specific nursing practice problem, contributing/causative factors and strategies that could have been used to enhance the outcome
- how to function in clinical situations where there is no clear right answer or standard procedure
- how to develop decision-making and problem-solving skills.

Cultural competence training for after-hours staff is an important component in creating a service that provides culturally appropriate care (Aleksandric and Hanson for PCA 2010). Aleksandric and Hanson (for PCA 2010) state that a culture-centred and person-focused approach is required when providing services to Aboriginal or Torres Strait Islander Australians to provide appropriate healthcare, as these groups can hold different views about end-of-life decision making (such as around autonomy, truth telling, communication and attitudes to medication).

Hauer and Quill (2001) state learning is a continuous process of integrating new and previously acquired knowledge or experience. They state that education programs should identify the target group's prioritised learning needs, have objectives based on specific knowledge/skills/attitudes, use established and appropriate teaching methods and be evaluated in terms of desired individual and clinical outcomes, and be continuously improved.

After-hours nursing support

After-hours face-to-face nursing care for community palliative care clients is provided by specialist palliative care nurses or district/community nurses. After-hours staff should offer a nursing visit where available and necessary, including if the client has called three times on the one day (Skinner 2001). There is an expectation that all community palliative care services will offer equitable services regardless of location (Tan et al. 2009); however, due to funding and workforce shortages, after-hours on-call nursing services are not sustainable in some rural and regional areas (Hahne et al. WMC/WHCG 2011; Worth et al. 2006). After-hours visits can also be too dangerous to undertake in certain areas due to issues posed by large distances and the local environment (Tan et al. 2009; Devlin and McIlfatrick 2010). Tan et al. (2009) assessed that there is a current need for more nurses to be available for home visits, support and debriefing after hours. The cost of providing these services includes on-call hourly pay rate plus penalties, car and phone costs, security service costs, on-call staff breaks and related staff replacement costs in hours. Costs are currently packaged or absorbed into the general service operating costs (Wellman 2007).

District and community nurses providing day-to-day shared care and on-call after-hours support to palliative care clients are multiskilled generalists, with palliative care comprising a small portion of their daily workload (Robinson et al. 2009). Tasks they are responsible for include personal care, medication administration, regular assessments, appropriate referrals and identifying deteriorations in condition (Devlin and McIlfatrick 2010). Half of the district/community nurses surveyed by Smith and Porock (2009) thought that palliative care training was not available, not easy to access or that training was not provided to new staff. In fact one-quarter of staff they surveyed did not think care for the dying would be part of their nursing role prior to their employment. Devlin and McIlfatrick (2010) found that any knowledge generalist nurses had was mostly learned 'on the ground' from co-workers.

The majority of nurses in the Devlin and McIlfatrick (2010) study said they were clear about their role in end-of-life care but that it could sometimes be more stressful than working with other clients due to: the emotional demands it created; the uniqueness of each situation; having to answer difficult questions; having to manage uncontrolled pain and other distressing symptoms; and physical deterioration and clients with cognitive or communication impairment (Devlin and McIlfatrick 2010). A nurse's comfort in providing palliative care can be influenced by their knowledge of and attitudes to care of the dying (Smith and Porock 2009; Robinson et al. 2010). District/community nurses are also under caseload and time pressures, which prompts comments that it is difficult to provide emotional support for palliative clients. On the other hand, discomfort in providing certain care may be hidden by the excuse of time pressures (Smith and Porock 2009).

Smith and Porock (2009) stated that effective palliative care nursing education should commence at induction to a service, with regular and consistent mandatory updates if they are expected to provide safe, effective care. Palliative care courses and study days for district/community nurses are usually provided by community palliative care, non-government industry bodies or hospice services (Smith and Porock 2009). Additional specialist palliative care training can be gained through the completion of relevant postgraduate diplomas or certificates (Wellman 2007).

A United Kingdom study with district/community nurses providing after-hours palliative care found that 50 per cent of respondents felt that hospital admissions were unavoidable; however, a lack of communication or difficulties mobilising rapid response services in crisis situations were seen to be the main causes (Smith and Porock 2009). Key to this is a lack of access to palliative medications

after hours if not previously ordered or placed in the home (Wellman 2007). The nurses' satisfaction changed to a sense of failure and 'damage caused to the client' when after-hours support broke down due to insufficient planning or local resources available to facilitate clients dying at home and one-quarter felt they lacked support and supervision when dealing with distressing situations (Smith and Porock 2009).

Concern about staff safety can be a barrier to providing after-hours nursing visits, especially in rural areas (Tan et al. 2009). Some services may chose to send two staff, send security staff to accompany nurses, use supervisors to call visiting nurses within 30 minutes of a call out to ask yes/no security questions (or the use of code word answers), or require the visiting nurse to contact a local hospital or security service once the visit is completed (Wellman 2007).

After-hours medical support

Tan et al. (2009) and Wellman (2007) found the priorities for the development of after-hours palliative care services to be the ability to access specialist palliative care advice and medications and the availability and affordability of after-hours GP and locum services. Access to telephone advice from specialist staff is a universal requirement for GPs and district nurses; however, demand for palliative care medical specialist after-hours visits is in the main seen as insufficient to warrant a visiting service (Worth et al. 2006). Robinson et al. (2010) note that rural access to non-local specialists is important but it must occur is a way that does not undermine GPs as the mainstay of rural palliative care.

GP workforce shortages are a critical factor in the ability of the profession to meet demand for after-hours services (AMA 2004a). Most are already working overtime, with increasing care burdens resulting from early discharges and increased client complexity (Tan et al. 2009). The AMA (2004a) state there are gaps in the remuneration incentives for after-hours GP practice and that GP attitudes to after-hours work have changed, with the increase in numbers working part time (due to workforce ageing, prioritisation of lifestyle factors or family support needs, particularly with the rise of the female GP workforce). Taubert and Nelson (2010) found that remuneration, as well as an ability to opt in, were the key motivators for GPs practising after hours.

Tan et al. (2009) found that in most urban and semi-rural areas the GP after-hours service is provided by locums; however, 17 per cent did not have a locum service available in their area and the case is worse in rural and remote areas, with 93 per cent not having access to a locum service. Studies with after-hours GP and locum services in the United Kingdom have found that often acute conditions will take precedence over end-of-life care, with doctors stating that palliative cases generally took up more time and required more sensitivity than general cases, therefore adding significantly to the time pressures they may be under on a particular shift (Worth et al. 2006, Taubert and Nelson 2010). A mix of having to change mindset to a palliative approach, unfamiliarity with the patient, patient/family suspiciousness of after-hours services and coming into the patient's life at a time of drastic change can also create a very stressful situation for GPs visiting after hours (Taubert and Nelson 2010). The AMA (2004a) states that some GPs create unrealistic expectations among clients about the available after-hours services (such as wait time, cost and as a good alternative in an emergency).

Tan et al. (2009) report that there is a gap in the palliative care training of GPs. Cooley et al. (2010) state that palliative care knowledge development among clinicians needs to be linked to practice competence via introductory, generalist and specialist education streams. GP willingness to provide palliative care or a palliative approach is found to be directly influenced by their palliative care knowledge (Robinson et al. 2010).

The AMA (2004a) states that any after-hours medical model (not only for palliative care) needs to be:

- GP centric and supported by local GPs
- driven by well-defined clinical need
- based on clearly defined objectives and credible evidence
- locally appropriate and supported by the community
- linked to community education regarding available services and appropriate use
- include funding for infrastructure (visits, IT, fee for service, links to existing services)
- based on processes and procedures that ensure continuity of care
- evaluated and have a built-in quality improvement cycle
- measured against professional standards.

Blance (1997) and Tan et al. (2009) also feel that support interventions are needed for all on-call medical staff (as well as nursing staff) undertaking after-hours work with palliative clients.

Using volunteer staff

A large palliative care medical specialist telephone consultation service was implemented in Maryland in the United States, primarily to provide timely advice on effective urgent pain management. The clinicians manning the 'hotline' were volunteers who were board certified by the American Board of Hospice and Palliative Medicine. The service aimed to legitimise the specialty of palliative medicine among the wider medical community. Use of the service peaked after the initial marketing program and settled to three calls a month after 10 months of operation. The process taken to set up the service was:

- identifying an interest group
- identifying a funding source
- solicitation for volunteers
- arranging first and second on-call/first and second month schedule
- arranging an answering and paging service
- marketing via clinician publications and magnets
- a data collection program that compiled call time and date, caller profile, return telephone numbers, problems getting volunteer response requiring contact with second on call
- evaluation of efficacy and cost.

Volunteers for the service were legally protected under the state's Good Samaritan laws and clinicians provided advice based on a case scenario as they saw this as similar to online threaded discussions or symposium case presentation and discussion. Gloth and Schwartz (2000) advise that it is always safest to consult with legal counsel or the state's Attorney-General whenever legal concerns arise while trying to develop a similar hotline.

Activity following an after-hours contact and quality assurance

After-hours support staff may experience stress related to their proximity to deteriorating and dying clients. Qaseem et al. (2007) found that the main issues impacting on job satisfaction among 599 hospice staff included communication, workload issues, autonomy and co-worker and management feedback and support. The key influencing factors included meaningful and challenging work, opportunity for growth/promotion, professional commitment to hospice care, collaborative and interdisciplinary working relationships, feeling valued and availability of emotional support.

Blance (1997) found that hospice staff support needs should be addressed via individual appraisals, support groups and information gatherings, and aim to enable and empower staff to look at their own situation and recognise their own ability to deal with stress and grief. They recommended a long-term course (2.5 days of content presented over 8–12 weeks) that addressed recognition of stress and grief, use of communication skills/assertiveness and developing appropriate mechanisms/support for dealing with stress.

Skinner (2001) stated that it is an important after-hours service responsibility to document the calls and interventions occurring after hours and transmitting that information back to the home care staff and that to provide continuity of care, this information should be fed into the wider plan of care for the client. Elliker and Barnes (2008) suggest that GPs should also be informed about an after-hours contact from a community palliative care client. Yardley et al. (2009) state that this documentation should meet the same standards as any other nursing consultation, with the appropriate information passed immediately to the relevant community service.

O'Connor et al. (for PCA 2009) state that research to support evidence-based practice is paramount to (service) quality assurance and effectiveness. Governments and the palliative care sector will need more precise measures of service activity in the future due to an increased need to examine the efficiency, quality and safety of delivery of publicly funded health services (Thick 2010). Financing and system performance is one of the five key building blocks for the *Australian National primary health care strategy* (DoHA 2010). Common patterns can emerge in service utilisation that can be used for community palliative care services planning and staffing allocation (Phillips et al. 2008).

In terms of after-hours quality assurance, Yardley et al. (2009) recommend a regular review of call advice within 24 hours via audit and caller feedback. Phillips et al. (2008) suggest case reviews should include reading case notes and call data, establishing what the expectations of the caller were and what their perceptions of the services' effectiveness were post contact. Finally, Schulz et al. (2009) recommend reviewing an after-hours service via a staff self-applied/multiple choice questionnaire and/or clinical exam, a client questionnaire or interviews, stakeholder group discussions, individual case reviews and expert or peer review real or simulated client contact with the service (incognito 'mystery shopper' style).

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