



Out-of-hours Palliative Care Considerations and Suggestions from Voices4Care Members

Background

All Voices4Care members were invited to a Voices4Care meeting in Dublin on 9 August 2019 and 21 members attended. At the meeting there was a workshop on out-of-hours palliative care support. The information gathered at this session is summarised in this report and will also inform the 8th Annual Palliative Care Research Network (PCRN) Symposium being held on 14 November.

The PCRN Symposium is an island of Ireland event that promotes the impact of palliative care research to improve practice and change policy in palliative care. This event supports early, mid-career and senior researchers in palliative care and associated health research areas on the island. The theme of this year's symposium is 'out-of-hours palliative care' which is the top research priority in palliative care on the island of Ireland.

Workshop

A workshop took place at the Voices4Care meeting to ensure representation of the views of people with palliative care needs, families, carers, and interested citizens at the symposium in relation to out-of-hours palliative care.

In three groups, members discussed three questions in relation to out-of-hours palliative care as below:

- Q 1. What do you think is important to consider palliative care outside of normal working hours? *They can be either positive or negative.*
- Q 2. What sort of palliative care support do you think should be provided outside of normal working hours?
- Q 3. Where should this out-of-hours care be provided and by whom?

Each group wrote down their main discussion points and presented their feedback to all members present on the day. Their comments and feedback were collated by AIIHPC and several main themes emerged.

Results

Equality, accessibility, and availability of out-of-hour palliative care services

- There tends to be uneven provision of out-of-hours care, geographically etc.
- It was highlighted that a Palliative Care Nurse is available, but only one person, who is overused and therefore not available for a whole area.
- Some GPs do not know what support there is for the patient and what to expect.
- There is stress for family members/carers if support isn't available and there tends to be a breakdown of services in emergencies.

Suggestions: Services need to be 24/7, nurse (e.g. Macmillan) and out-of-hours doctor support, carers provided (3 times per day), first aid support, ambulance support (e.g. St John's Ambulance), and signposting for advice. Marie Curie Rapid Response service in Northern Ireland was suggested as a good model.



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Continuity of palliative care at home

- Continuity of care is a clear aim of palliative care services.

Suggestions: A plan could be developed to ensure this continues at home and out-of-hours. This would include a clear plan of action recorded in a folder for the patient at home (reviewed weekly) and recognised by the hospital, including advance care directives and emergency response in the event of medication required. In the event of an emergency response where should appropriate medication come from? Potentially the hospice, who can mobilise the ambulance to deliver the medication. There should be availability of medical records to allow for continuity of care between healthcare professionals and providers (unique medical number and electronic records). It was suggested that family/carers/person with palliative care needs could hold and provide medical records/contacts in the event of requiring care out-of-hours.

Out-of-hours medication/pain management

- There was a consensus that medication and/or pain management could be managed in a way to help reduce stress for patients and families.
- It was discussed that pain relief is not available for carers to administer, that not the same (appropriate) medication is given out-of-hours and that access is needed to recommended medications. These issues can cause patient and carer distress.
- Also, that palliative care could be officially available and can therefore mobilise the right sources of pain relief at home or nursing home. Hospital seems to be the main place for pain control.
- GPs are risk adverse about pain relief.

Suggestions: Anticipatory pain relief needs (ensuring supplies are accessible when needed) should be prescribed. It would require GP out-of-hours access to medical records. It was suggested that there could be someone/centres available to dispense and/or prescribe appropriate medication and give advice. It was felt that education for GPs on prescribing for palliative care could improve continuity of care at home. Access to medical records, key information (e.g. history) needs to be with the patient, having access to an experienced health care professional to contact for advice. Support for the carer – knowing what to expect (at times not inclusive of carer in communication).

Out-of-hours palliative care medical emergency response

- A&E are not prepared to deal with an emergency with regards to palliative care.
- Information is not provided, and this puts family members under stress, with them having to deal/sort out the problem.
- There is no continuity in GP practices.

Suggestions: Carers need support, along with information on what to expect (sometimes carers are not included in important communication). An out-of-hours medical emergency plan could help with these issues. It should include how to contact an experienced health care professional for advice, out-of-hours doctor backup to palliative care specialists, direct access to palliative care if patient is diagnosed and known to palliative care, pain relief/anticipatory prescribing, advance care directives, and out-of-hours number for



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hospice. A consideration of note, what is the emergency response if something happens to carers outside of hours?

Support networks (informal and formal) that enable the continuation of care at home

- The need for support for families/carers was highlighted, that there is a need to connect informal networks (groups) with formal networks.
- It was discussed that it is difficult to get support during night, that care is left to the family.
- Ideally care at home for as long as possible but is the expectation on family to provide the care?

Suggestions: One palliative care support hub could exist for patients and families. This hub could identify the need and action (triage) and that this may take the burden off the family and carers. Other suggestions included the development of a rota of support from family/friends, that palliative Care Services can direct carers to support, and the creation of a 'pool' of volunteers in a local community. Palliative team should be available out-of-hours and back up services.

Other comments

- Language and culture (changes North and South, adopting and adjusting, being aware of issues)
- Home Care = cost / impacts on job etc. of carer
- Improved technology – invest – share information
- Health care professionals need skills and knowledge
- Who should be providing care should be GPs as palliative care team in hospice
- Services declined where patient wants it within reason
- Need for professionals to support conversation/communication
- Ability to have choice of location – within reason
- Lack of resourcing
- Dependent on individual / family / situation
- Ability for families to stay with patient