Introduction

This guidance is for health professionals caring for patients who may need referral to specialist palliative care services within the South West Wales Palliative Care Network. It does not represent new policy on service provision but rather describes arrangements for the existing and ongoing services. It is supplemented by local guidance and by local referral forms. The constituent services in the network are influenced and constrained by different factors, including geography. Provision and documentation will therefore vary. All providers, however, operate within the framework described here.

Specialist palliative care is provided for patients whose disease is no longer amenable to curative treatment. Not all patients who fall into this category, however, need specialist palliative care. Palliative care is quite rightly provided to them by the health professionals who are caring for them whether in primary or in secondary care. All teams should make use of locally & nationally available guidelines for advice on use of first line drugs in symptom control. Specialist palliative care is needed when there are problems needing more intensive or more expert input and the guidance here is intended to help professionals to identify which patients might benefit from referral. It is hard to define precise distinctions however between those who do and those who do not need specialist palliative care. For this reason, informal contact (by phone, or face to face, or through site-specific cancer MDT meetings) for advice on the appropriateness of a referral is encouraged.

Ongoing active treatment should not delay referral of patients who may benefit from specialist advice. Increasing numbers of patients with cancer are benefiting from active oncological treatment with palliative intent. Many of them also have palliative care needs and prompt referral should be considered.

Although specialist palliative care is usually concerned with advancing disease there may be patients with curable disease who can benefit from this expertise, for instance in the management of more complex cancer pain. Early discussion is encouraged for advice or with a view to a referral.

Historically most specialist palliative care teams have dealt predominantly with patients with cancer. Many have supported a small proportion of patients with other diagnoses; some have had no experience of this. There are some local arrangements for provision of care but there is incomplete consensus on how the services should progress. The important questions about the quantity and nature of need in this population are as
yet incompletely answered. Service developments should be informed by the answers to these questions as they become available. The use of a specialist palliative care approach by teams caring for patients with advancing life-limiting disease from any diagnosis is to be encouraged.

In any circumstances the referrer must see the patient before making a referral. Accurate and current information is essential to the prioritisation of the referral and to the team’s assessment in response. Referrals for urgent assessment, and especially for admission, should not be made if more than a working day has passed since the referrer saw the patient.
**Referrals to the service**

Refer if the patient

- has progressive disease with an appropriate diagnosis (local variation; for non-cancer diagnoses discuss with local team)
  
- AND
  
- lives within the area covered by the service OR is registered with a GP within the area covered by the service OR is a hospital inpatient
  
- AND
  
- is willing to see the palliative care team (if able to discuss), OR if patient is not able to discuss then relevant carer is aware of the referral to the team unless there is clear reason not to inform them
  
- AND
  
- has one or more of the following:-
  
  - pain related to progressive disease uncontrolled by simple analgesia &/or first line strong opioid &/or 1st line adjuvant
  
  - other physical symptom(s) uncontrolled by 1st line of drug treatment
  
  - any severe related symptom uncontrolled within 48 hours of starting treatment of it
  
  - symptoms uncontrolled after 48 hours in rapidly progressive disease
  
  - psychosocial distress in patient or family concerning progressive illness, dying or related issues
  
  - need for support and additional opinion on decisions such as whether treatments including artificial nutrition and hydration should be withheld or withdrawn
  
  - need for further assessment of complex symptoms or other problems, or ongoing specialist support at home, following hospital discharge
  
  - dying complicated by physical symptoms, psychological, social or spiritual distress in patient or family, complex care needs or other aspects of care for which specialist palliative care support or advice would be helpful
Who can refer?

There is local variation. Throughout the network referrals are accepted from a GP or hospital doctor involved in the patient’s care. When a patient is moving between hospital and community or between geographical areas the referral may be made by the specialist palliative care team which has been supporting the patient. This referral should be made by the referring team member best placed to give the information necessary for the receiving team to prioritise and act on the referral. Discussion by phone is encouraged: these patients often have complex and evolving needs, and because different teams have different practices close cooperation is needed to ensure that the patient’s and family’s expectations are in line with what will be provided by the receiving team. For hospital inpatients the permission of the responsible inpatient team may be needed.

Many services accept referrals from appropriate nursing staff, the patient or relevant carers. Contact the local service for advice.

What to refer for?

Referrals can be made for: support from the hospital or community palliative care team (according to the patient’s location); day care (details vary by area); or admission. Referrals should indicate which service is being requested, although of course different parts of the palliative care team will refer to each other as appropriate – for instance, referral to hospital or community palliative care teams will lead to consideration of whether inpatient admission is needed.

How to refer?

Referrals should be made on the referral form for the local service. Contact details are provided on the form. Urgent referrals are accepted by some services without a standard form if using a form would delay the referral – contact the service in question for advice on this.

Urgency of referrals

Referrers should indicate the urgency of the referral as they see it. Description of the urgency is helpful so that the team can prioritise among referrals from different sources. Specialist palliative care teams are not responsible for providing an emergency response (although within their working hours they may sometimes be able to respond rapidly) and emergencies are the responsibility of the primary health care team or
hospital team as appropriate. Urgent referrals should be discussed by phone if possible. Patients referred urgently will be seen within two working days where possible in line with national standards.

**Outcome of referrals**

Intervention by the team will be at one of four levels:-

**Level 1** Advice and information is offered to professional colleagues directly by the team. The team will make no contact with the patient.

**Level 2** The team makes an advisory visit. Such visits will be single, unless requested otherwise by the referrer, and further contact will be made by the professional referrer only.

**Level 3** The team makes short-term interventions with the patient or family when specific problems need several visits. The intention is then to withdraw. Further referral may be made as necessary.

**Level 4** The team makes multiple interventions. There are ongoing problems requiring continuing, regular assessment.

**Ongoing communication**

Referrers will be informed of the outcome of a referral and may be given information on progress at other times. If it is not appropriate for the patient to be taken on then advice may be available about alternative strategies.

In return it is the responsibility of the referrer to continue to communicate necessary information to the specialist palliative care team, for instance on significant investigations, changes in treatment, information given to patient and family. The easiest way to communicate this is for all correspondence to be copied to the appropriate member of the palliative care team.

**Referrals for admission to hospice or specialist palliative care unit**

Admission is normally arranged by the specialist palliative care team appropriate to the patient’s current location. Most patients for whom admission is appropriate will already have been referred to the team but local arrangements may provide for admission of patients not previously referred when this is needed. **Requests for admission should be discussed with the team before admission is offered to the patient or family.**
Indications for Admission

Symptom control:
Admission is offered when it could help to address uncontrolled or difficult physical or psychological symptoms (or other related problems).

Terminal care:
Terminal care is here means care during the last several days, up to about the last two weeks, of life. Admission is offered when the current or alternative place(s) of care are not suitable because of specific aspects eg evolving symptoms, changing condition complicating control of symptoms, psychological problems, nursing care needs, family support needs. The needs to be addressed should be those that can be best met by a specialist palliative care unit.

Respite:
Planned or emergency respite may be offered locally depending on local provision and available alternatives to meet this need. Very often the need for respite can be met without the use of a specialist palliative care bed where alternatives such as community hospital, nursing home or short term intensive nursing care at home are available and suitable. Exploration of the full range of options is encouraged, with discussion with local inpatient unit where appropriate.

Discharges from the service
For some patients the goals of the referral to the specialist palliative care team are met over time and further input from the team is not needed. Some patients at this stage themselves prefer to have no further input. Where the team perceive no indication for continuing input with a patient and family, discharge from the service will be discussed with the patient, family if appropriate and primary health care team (for patients at home) or hospital team (for hospital inpatients). The patient may then be discharged, preferably by mutual agreement and generally following discussion with relevant parties.
Guidance notes on typical role distinctions of primary or hospital teams and specialist palliative care teams. These lists are not exhaustive. Contact the local team if in doubt.

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<thead>
<tr>
<th>Role of the Community/Acute Teams (with advice from the Specialist Palliative Care Team)</th>
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<tbody>
<tr>
<td>When use of WHO pain ladder and appropriate adjuvants result in incomplete analgesia, and or unacceptable side effects. Escalating uncontrolled pain and other symptoms. Complex symptom control problems, incomplete symptom control problems.</td>
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<tr>
<td><strong>Psychological and spiritual support for patient, care and family</strong></td>
<td>Assess level of insight and current situation and provide psychological and spiritual support. Review and reassess as necessary. Document outcome.</td>
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<td>Advice and support for complex problems, dysfunctional family dynamics where these are relevant and amenable to intervention and where patient and family will accept it.</td>
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<tr>
<td><strong>End of Life Care</strong></td>
<td>Identify that the patient is dying. Ensure appropriate symptom control, psychological support. Review and reassess as necessary. Document outcome.</td>
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<td>When specialist support is required to achieve appropriate symptom control, psychological support and spiritual care.</td>
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<tr>
<td><strong>Bereavement Support (where available)</strong></td>
<td>Negotiate who is appropriate to give bereavement support.</td>
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