





# How to refer to palliative and end of life care services in South and West Hertfordshire



We are the palliative and end of life care providers supporting patients registered with a GP in South and West Hertfordshire.

We are united in our goal to provide a seamless and supported journey for patients across South and West Hertfordshire.

### How to refer

#### 1. Complete a referral form

All palliative and end of life referrals from healthcare professionals working in South and West Hertfordshire need to go through West Herts Palliative Care Referral Centre (PCRC), click <u>here</u> for the referral form.

#### 2. Call

For urgent referrals or to discuss a potential referral, healthcare professionals can call West Herts PCRC on **03000 200 656** followed by option **2** then option **0** (9am-5pm, 7 days per week).

For out of hours advice (including how to refer out of hours), healthcare professionals can call the Out of Hours Advice Line on **01923 335 356**.

If you want to refer a patient who is within the acute setting, please contact the palliative care service within that hospital.

### When to refer

We can help patients from the moment they are diagnosed.

We support patients, and those close to them, for as long as they need us, not just the last 12 months of life.

We are here for patients with all progressive life-limiting illnesses, including cancer, heart disease, motor neuron disease, progressive respiratory disease and Parkinson's disease. We also support people living with frailty.

Click <u>here</u> for **Referral Tips**.

Palliative and end of life care is provided by multidisciplinary teams, which include medical, nursing and Allied Health Professional (AHP) colleagues working in both NHS and charity organisations – across primary and secondary care, and hospice settings.

### Services

#### **Outpatient services**

Patients have access to nurse-led clinics and assessments, as well as specialist medical input and programmes that help them to live with a progressive life-limiting illness, as well as provide support and direction to patients on a curative journey.

#### **Rehabilitation and wellbeing services**

*Courses, classes and group sessions* – Exercise classes are available and help with breathlessness and fatigue, plus creative therapy. The classes, led by occupational therapists or physiotherapists can help with symptoms and treatment side effects.

*Complementary Therapy* – therapies include Reflexology, Relaxation, Meditation, Massage, Reiki, Acupuncture and Scar therapy.

#### **Psychological services for patients**

Listening and Talking Therapies provide emotional support for people who are experiencing life-changing illness. See <u>pages 5 and 6</u> for support for family members and carers.

#### Specialist support groups

Specialist support groups, such as the Pulmonary Fibrosis Group and Heart Failure Group, are available for patients and those close to them.

#### Palliative social worker services

Palliative social workers help patients with palliative care needs, and those close to them, to feel more in control of their life challenges, including support accessing resources and services within their community, including benefits advice.

#### **Benefits advice**

Welfare and benefits advice is available for patients and their families.

#### **Spiritual support services**

Providing spiritual support to patients who are receiving palliative care has been shown to have markedly positive effects on a range of health outcomes.<sup>1,2</sup>

#### Community specialist palliative care services

24/7 support is available for patients who choose to receive care at home, including care homes. It is delivered by a combination of providers.

Assessment – A specialist community nurse assesses the patient's needs and works with the patient and a member of the multidisciplinary team, to create a personalised care plan, which will include avoiding inappropriate hospital admissions.

#### Rapid Personalised Care - personal care in the last 12 weeks

When a patient is "rapidly deteriorating" and their prognosis is likely to be less than 12 weeks, they can be referred for personal care support in their own homes.

#### Inpatient care in a hospice

#### Short stay care and end of life care

The two Inpatient Units in South and West Hertfordshire (The Rennie Grove Peace IPU in Watford and The Hospice of St Francis IPU in Berkhamsted) take patients for symptom control, complex situations, end of life care and rehabilitation.

After a short stay, if appropriate, patients are discharged for ongoing care in community or nursing home settings.

### Services with different referral routes

Some services, particularly for family support, do not go through West Herts PCRC and enquiries must be sent directly to individual services. To self-refer, patients can call the provider directly or go to their website.

If you are unsure how to refer to these services, call West Herts PCRC on **03000 200 656** followed by option **2** then option **0** (9am-5pm, 7 days per week).

#### Community Support Hubs - drop-in (click here)

An informal space where people who have been affected by the diagnosis of a progressive life-limiting illness can drop in to meet others for a drink and a friendly chat. Trained volunteers offer information, guidance and signposting to available services.

#### **Carers' services**

Individual and group support is available for carers, covering practical, financial and psychological support for those caring for others. This includes, a pre and post bereavement group for children and young people, plus one-to-one sessions.

Rennie Grove Peace carers' services

Hospice of St Francis carers' services

#### Compassionate Neighbours (click here)

The Compassionate Neighbours scheme helps to reduce isolation and loneliness in patients with a progressive life-limiting illness. A trained Compassionate Neighbour volunteer supports people at home, providing companionship and practical support.

#### Marie Curie support (click here)

Marie Curie provides one-to-one care and support overnight in a patient's home.

#### Bereavement and support services

Trained counsellors offer a wide range of bereavement support for adults and children, in group or one-to-one sessions – at home, in one of our hospices, in a child or young person's school setting, or via video call or phone. Drop-in bereavement groups are also available.

Hospice of St Francis bereavement support

Rennie Grove Peace bereavement support

#### Compassionate Cafés (click here)

These drop-in sessions, in local cafés and venues, provide a welcoming space for people affected by any type of loss.

#### Education and support for care home staff

Patients living in a care home who need individual support should be referred in the usual way via West Herts PCRC.

Training and support is available on request to care home staff to help them better support their patients with palliative and end of life care needs.

Rennie Grove Peace training for care homes

Hospice of St Francis training for care homes

## **Referral tips**

**Refer as early as possible** – With earlier referrals, we can help patients live well for longer.

**Call if urgent** – If an urgent response is needed outside the hours of 9am-5pm and the patient is not already known by a specific Specialist Palliative Care team, call the Out of Hours Advice Line on **01923 335 356**.

For urgent referrals, healthcare professionals can call West Herts PCRC on **03000 200 656** followed by option **2** then option **0** (9am-5pm, 7 days per week).

**Include as much clinical information as possible** – Complete all the fields within the referral form and include as much information as possible. Clinical letters and medication lists are helpful.

**Identify and include the patient's Phase of Illness and their AKPS** – Identify the patient's Phase of Illness and their AKPS (Australia-modified Karnofsky Performance Status) which is a measure of the patient's overall performance status. See the following tables:

Phase of Illness	Patient is in this phase when
Stable	Patient's problems and symptoms are adequately controlled by the established plan of care and further interventions to maintain symptom control and quality of life have been planned and family/carer situation is relatively stable and no new issues are apparent.
Unstable	An urgent change in the plan of care or emergency treatment is required because the patient experiences a new problem that was not anticipated in the existing plan of care and/or the patient experiences a rapid increase in the severity of a current problem and/or family/carer circumstances change suddenly impacting patient care.
Deteriorating	The care plan addresses anticipated needs, but requires periodic review, because the patient's overall functional status declines and the patient experiences a gradual worsening of existing problem(s) and/ or the patient experiences a new, but anticipated, problem and/or the family/carer experiences gradual worsening distress that impacts the patient care.
Dying	Dying: death is likely within days

#### Phase of illness

#### **AKPS Assessment Criteria**

AKPS Assessment Criteria	Score
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

This leaflet has been put together by the following organisations:







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#### References

- 1. Cherny NI, Fallon MT, Kaasa S, et al. Oxford textbook of palliative medicine. 5th ed. Oxford University Press; Oxford: 2015. [CrossRef] [Google Scholar]
- Groot M, Ebenau AF, Koning H, Visser A, Leget C, van Laarhoven HWM, et al. Spiritual care by nurses in curative cancer care: protocol for a national, multicentre, mixed method study. J Adv Nurs. 2017;73:2201–7. doi: 10.1111/jan.13332. [PubMed] [CrossRef] [Google Scholar]