

# REFERRAL, ADMISSION, DEFERRAL AND DISCHARGE GUIDELINES TO ST WILFRID'S HOSPICE, CHICHESTER FOR SPECIALIST PALLIATIVE CARE



**St Wilfrid's Hospice**  
CHICHESTER  
Registered Charity No. 281963

**St Richard's Hospital  
Local Referral and  
Management Guidelines  
Committee**

**Palliative care** is an approach that seeks to improve 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 the assessment and treatment of pain and other physical, psychosocial, and spiritual problems. (Adapted from the WHO definition, revised 2002.)

Service provision and development is informed by the Department of Health's initiatives in palliative care and the **End of Life Care Strategy** <http://www.endoflifecareforadults.nhs.uk/eolc/>. St Wilfrid's Hospice [www.stwh.co.uk](http://www.stwh.co.uk) works with other healthcare professionals providing care in these areas and offers specialist care and advice for those with complex needs.

## REFERRAL CRITERIA

Patients requiring specialist palliative care who are 18 years of age or older with an active, progressive, advanced and terminal illness & a complex level of need.

**Prognosis** A terminal illness is defined by a prognosis of less than six months, although patients may occasionally be accepted for care irrespective of prognosis where the remaining criteria are met.

**Diagnosis** Patients are accepted for care with any diagnosis – not only cancer and motor neurone disease.

**Complex level of need** means exceeding the skills, facilities etc of an appropriately resourced primary health care team (including community matron or disease-specific nurse specialist), hospital ward or residential/nursing home. Complex needs can be patient, carer or health care team centred and the help required may be intermittent or continuous depending on the level of need and rate of disease progression.

**Areas of expertise** SWH offers in-patient care, day hospice and community support and is able to work with patients, carers and professionals to address problems in one or more of the following areas:

- multiple, complex or refractory physical symptoms
- complex end of life care
- difficult social, psychological and spiritual issues
- complex family and carer needs requiring specialist support
- bereavement support to families and carers of former patients

These patients are defined as having specialist palliative care needs. Patients whose sole need is for basic medical and nursing care do not meet the referral criteria. If a patient does not have specialist palliative care needs they will not be taken on for follow-up.

## WHEN TO REFER?

The appropriate time for a referral depends on many factors including the patient, the disease and the situation. These circumstances are so varied that it is hard to encompass them simply – but basically refer a patient when they meet the referral criteria above. A member of the hospice clinical team is always willing to discuss a specific case on the telephone before a referral is made.

## WHAT IS, AND WHAT IS NOT, THE ROLE OF SPECIALIST PALLIATIVE CARE?

The Hospice's specialist role is to support generalist palliative care provided by an appropriately resourced primary care team or hospital ward, and not to replace such care.

## GOLD STANDARDS FRAMEWORK

In most cases patients for whom referral to specialist palliative care is appropriate should be included in their GP's GSF register <http://www.goldstandardsframework.nhs.uk/>.

## CATCHMENT POPULATION

**Catchment population for community, in-patient and day care** The catchment population is made up of the patients of general practitioners based in the Sussex coastal plain from Emsworth to Arundel, encompassing Chichester and Bognor, and Hampshire patients from the Emsworth GP practice. This is a population of about 174,000 people. Occasionally patients who are not in the catchment population will be accepted for care at the Hospice if their acute care takes place at St Richard's Hospital or their family live in the catchment population.

**Patients from north of The Downs** Patients with GPs in Midhurst, Petworth, Pulborough, Billingshurst and Loxwood may be offered admission or day care following consultation with, and agreement from, the Midhurst Macmillan Team.

## REFERRAL MECHANISM

- Referrals are accepted from general practitioners, consultants, clinical nurse specialists, community matrons and by clinical staff acting on their behalf and with their knowledge. Ideally the patient's GP should be advised of the referral.
- Referrals are not accepted from patients or families directly – they will be advised to contact their GP.
- The hospice referral form is available on the hospice website [www.stwh.co.uk](http://www.stwh.co.uk).
- Completed referral forms should be faxed to the clinical secretary on 01243 538171. Referrals, with full details as per the referral form, may also be made by letter – faxed or posted to St Wilfrid's Hospice, Grosvenor Road, Chichester PO19 8FP or by telephoning the clinical secretary (on 01243 755813). The referral form will be completed by the secretary during the phone call.
- It is imperative that patients are told a referral to St Wilfrid's Hospice is being made; however it is not always necessary for patients to know the diagnosis or prognosis - although it is helpful.
- When discussing a potential referral with patients it may be useful to consider with the patient the particular needs for symptom control and palliative care at that time. It is important to explain that a referral does not necessarily imply immediate admission as this may help to allay some anxieties and fears.

## SERVICES OFFERED

Community support	Team of clinical nurse specialists
Inpatients	14 beds in single en-suite rooms, including two family rooms
Hospice At Home	A Hospice At Home team of both qualified nurses and health care assistants
Day care	Three days per week – Tuesday, Wednesday and Friday
Therapies	A team of occupational therapist and physiotherapist
Spiritual and psychological care	A team of chaplains and patient & family care specialists
Bereavement care	Team of trained volunteers co-ordinated by the Patient and Family Care Team
Complementary therapies	A range of therapies is available to patients and carers
Hospital team	Hospice consultants work closely with St. Richard's Hospital Palliative Care Team and a palliative medicine consultant or clinical nurse specialist attends all cancer MDTs
Education	Teaching programme for all healthcare professionals

## OUT OF HOURS SERVICES

- The CNS team is available Monday to Friday from 8.30am to 5.30pm, and one member of the team is on duty 8.30am to 5.30pm at weekends and Bank Holidays. The team does not provide a service out of these hours.
- The Hospice At Home team is able to support patients at home, and is available in normal working hours and outside the hours of 8.30am to 5.30pm. One health care assistant is available to support a single patient each night.
- 24 hour specialist support and advice is available by telephone provided by the ward nursing team. Telephone 01243 775302. If needed medical advice is also available, and may be accessed via the ward nursing team.
- Some admissions are received day-time at weekends. However the hospice is not staffed to take out of hours admissions. Appropriate emergency out of hours admissions are rare as increasing amounts of community support are put in place as a patient's condition deteriorates with the aim of supporting the patient and family at home. Patients with new acute problems, such as new haematemesis, should go to hospital.

## ASSESSMENT OF NEW REFERRALS

The initial assessment of community patients is undertaken by one of the medical, Clinical Nurse Specialist or patient and family care (psychosocial work) teams. Patients may also be assessed by one of the medical team in hospital or as an out-patient. Following initial assessment a plan for care is made, commonly community follow-up or hospice admission.

## **PATIENTS WITH ILLNESSES OTHER THAN CANCER OR MOTOR NEURONE DISEASE**

SWH accepts referrals of patients with any diagnosis.

However, identifying the role of specialist palliative care services in patients with an uncertain disease trajectory, for example, heart failure or COPD is difficult. The National Council for Palliative Care <http://www.ncpc.org.uk/> suggests that in most cases, palliative care services should provide “advice on aspects of symptom control for patients who remain under the care of another speciality”.

All patients with illnesses other than cancer or motor neurone disease should have a disease-specific CNS (if available), case manager, community matron and community nurse involved. SWH involvement will be in addition to, rather than instead of, such care.

## **ADMISSION CRITERIA**

Patients eligible for admission to the in-patient unit are those with

- multiple, complex or refractory physical symptoms requiring frequent medical review and/or intensive nursing care
- complex end of life care needing admission to a specialist unit
- difficult social, psychological and spiritual issues which may benefit from assessment and support in a specialist palliative care unit
- a requirement for convalescence, symptom control or complex discharge planning after a period of acute hospital care

The facility of admission to St Wilfrid's Hospice in-patient unit is additional and complementary to the care provided by the NHS and is not intended to be instead of NHS provision.

Many patients would choose to die at home, given adequate support – indeed enabling more people to die at home is the focus of the Department of Health's End Of Life Care Strategy. This must always be taken into account when considering an admission request to St Wilfrid's Hospice. The additional support required may be minimal and is available if the appropriate referrals are made.

When resources allow a pre-planned admission may be made to give a patient and/or family a break from care at home.

Patients are not accepted for in-patient hospice care on a long term basis. However some patients who have ongoing specialist palliative care needs may require an extended admission.

There may be occasions when it is more appropriate to admit a patient directly to a nursing home from home rather than admitting them to the hospice first.

Requests for admission are prioritised according to need by the hospice multi-disciplinary team.

## **EMERGENCIES AND ADVANCED RESUSCITATION**

St Wilfrid's is not able to manage acute clinical problems such as acute spinal cord compression requiring radiotherapy or surgery, fractures requiring surgery and neutropenic sepsis. In such situations patients should be referred to the relevant acute hospital. Facilities for advanced cardio-pulmonary resuscitation are not available.

## **DO NOT ATTEMPT RESUSCITATION ORDERS (DNAR)**

The hospice closely follows the West Sussex PCT DNAR policy which is available via <http://www.westsussexpct.nhs.uk/about-us/freedom-of-information/9-policies-and-procedures/policies-and-procedures/>. When appropriate, DNAR orders are made which are placed in the patient's home and copies sent to the GP, the ambulance service and Out-Of-Hours service.

## ADVANCE CARE PLANNING

St Wilfrid's is keen to support patients in Advance Care Planning (ACP), for example:

- Preferred Priorities for Care and death <http://www.endoflifecareforadults.nhs.uk/eolc/ppc.htm>,
- Lasting Powers of Attorney (LPA) <http://www.publicguardian.gov.uk/index.htm>,
- Advance Decisions to Refuse Treatment (ADRT) <http://www.adrtnhs.co.uk/>,
- Discussion around cardiopulmonary resuscitation (CPR) <http://www.resus.org.uk/siteindx.htm>.

Healthcare professionals making referrals to the Hospice may already have discussed ACP with the patient and should advise the Hospice of relevant information which may then be included in the patient's clinical notes.

## REFERRAL, FOLLOW-UP & ADMISSION DATA – April 2009

- The number of referrals received by St Wilfrid's is increasing annually and in 2008-09 approximately 700 new patients were referred.
- Around 55% of referrals are made by the primary care team and 45% from secondary care.
- The median length of stay on the in-patient unit is 11 days and 40% of patients are discharged home or to other places of care.
- The median stay for end of life care is 5 days.
- The median wait for admission is 1 day. The waiting list is monitored monthly.
- There are around 230 deaths per year on the in-patient unit.
- Approximately 5% of referrals are for patients with a diagnosis other than cancer or MND.

## DEFERRAL FROM FOLLOW-UP BY CLINICAL NURSE SPECIALIST

For some patients followed up by St Wilfrid's Hospice the need for specialist palliative care resolves after a period of time.

These patients will be deferred from active care and will receive occasional telephone contact from their clinical nurse specialist.

Deferred patients may attend day care or receive input from other hospice services which may be necessary, eg family care specialists.

Patients will be considered for deferral if

- their need for specialist palliative care (see referral criteria) has resolved, but is likely to recur in the near future

## DISCHARGE CRITERIA

If a deferred person's illness remains stable with no specialist palliative care needs they will be discharged from follow-up by all parts of the hospice team completely.

Some patients may move directly from active care to discharge without being deferred.

Around 10% of patients on the active case load are discharged in any year. Re-referral is welcomed if the patient subsequently develops specialist palliative care needs.

Patients will be considered for discharge if

- there has been resolution of multiple, complex or refractory physical symptoms
- the disease becomes stable and is no longer progressing quickly
- there is no longer a need for specialist, complex end of life care
- there are no longer needs for specialist palliative care follow-up and/or the patients on-going needs are more appropriately met by other health and social care agencies
- the patient's difficult social, psychological or spiritual issues have been addressed
- the family and carer needs requiring specialist support have been addressed
- the patient requests discharge or is reluctant to allow effective support, eg restricting access for assessment

A decision to discharge a patient will be made following multi-professional discussion to ensure that the issues above have been considered. The discharge will be organised in a planned way.

## PATIENT INFORMATION

A patient information guide regarding the services of the Hospice is given to patients at the initial consultation. This is also available on request to referring health professionals to give to patients at the time of referral. St Wilfrid's web site address is [www.stwh.co.uk](http://www.stwh.co.uk).

## CLINICAL PATHWAY

A clinical pathway has been developed as a pictorial representation of the patient pathway and is produced as a separate document which may be read in conjunction with these guidelines.

## PALLIATIVE CARE CLINICAL GUIDELINES

Standard clinical guidelines for symptom control in palliative care are used across the Central South Coast Cancer Network – the Wessex Palliative Care Handbook 2007 ("The Green Book"). The guidelines are distributed to local general practitioners and community nurses. Hard copies are available on request, and the guidelines are available to access or download from the hospice website. Also on the hospice website is a guide to opioid conversion ratios.

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