

## End of life care information for patients, carers and relatives.

Good end of life care is a priority at Emsworth Surgery. We understand that this can be a challenging and distressing time. Therefore, we have produced this information resource which aims to explain some of the common terms that you may encounter, services that are available and some of the financial/legal requirements.

### Common terms

**Palliative Care** - Holistic care of patients with advanced, progressive, incurable illness, focused on the management of their symptoms and the provision of psychological, social and spiritual support to patients and their families.

**Hospice** - Hospices provide specialist palliative care given by doctors, nurses and other health care professionals. Care is offered for patients with particular needs and difficult symptoms and can take place at patient's homes, day care and inpatient settings. Hospice care not only looks at improving physical needs but also looks at emotional, spiritual and social needs as well. Hospices are mainly charitably funded.

**Prognosis** - The prediction of the outcome of a disease based on the patient's condition and the usual course of the disease. It may be expressed as percentage e.g. the percentage chance of survival within a set period.

**Advance care planning** - This is a process for you to discuss and reflect about goals, values and preferences for your future treatment in the context of an anticipated deterioration in your condition, which could result in loss of capacity to make decisions and communicate these to others.

**Anticipatory medications** - These medications (often injectable) are prescribed by your GP in anticipation of managing symptoms that may occur near the end of life. These medications are kept at your home and can be administered by health care professionals. Common symptoms include pain, restlessness, breathing problems, vomiting and anxiety.

**Syringe driver** - A syringe driver is a small, battery-powered pump that delivers medication through a soft plastic tube into a syringe with a needle which is placed just under the skin. This is used when you are unable to swallow medications. A syringe driver is used to control symptoms and delivers a steady flow of injected medication continuously under the skin. It can be set up by your district nurse or palliative care team at home.

**Life limiting or terminal illness** - A condition or illness from which there is no reasonable hope of cure and from which a person is expected to die. This commonly refers to cancers but can include any progressive diseases.

**The end of life** - There is no clear cut definition of the 'end of life'. In general it refers to the last few days of life when a person is irreversibly dying, also known as the terminal phase. Whilst there are situations in which it is possible to identify the terminal phase with some accuracy, many diseases have a natural history of progression and exacerbations which makes the transition to the terminal phase difficult to identify.

### Financial/Legal

**Advance statement** - This is a general statement of your views and wishes. It can indicate the treatment you would prefer and how and where you would like to be cared for. An Advance Statement isn't legally binding, but your doctors should take it into account when deciding what's best for you.

**Advance directive** - This is a general term that describes two kinds of legal documents, living wills and lasting power of attorney (health and welfare). These documents allow a person to give instructions about future medical care should he or she be unable to participate in medical decisions due to serious illness or incapacity.

**Lasting power of attorney** - A lasting power of attorney (LPA) is a way of giving someone you trust the legal authority to make decisions on your behalf if you lack mental or physical capacity at some time in the future or no longer wish to make decisions for yourself.

There are two types of LPA:

1. for financial decisions
2. for health and welfare decisions

**Living will** - This is a type of advance directive in which an individual documents his or her wishes about medical treatment should he or she be at the end of life and unable to communicate. It may also be called a "directive to physicians", "healthcare declaration," or "medical directive."

**Capacity** - This is the ability of a patient to make a decision. An adult is deemed to have capacity unless, having been given all appropriate help and support, it is clear that they cannot understand, retain, use or weigh up the information needed to make a particular decision or to communicate their wishes.

**DNACPR** - Abbreviation of 'Do Not Attempt Cardiopulmonary Resuscitation'. These advance management plans may be called DNAR orders or Allow Natural Death decisions in some healthcare settings. This is not a withdrawal of regular treatment or care, it refers only to cardiopulmonary resuscitation after the heart has stopped.

**FP92A** - This is an exemption certificate for cancer patients in England for prescription charges. All cancer patients undergoing treatment for cancer, the effects of cancer or the effects of cancer treatment can apply for this certificate. Your doctor and you will need to complete this form.

**DS1500** - This is a form, completed by a GP, Consultant, hospital doctor or specialist nurse, which enables someone who is terminally ill to claim Disability Living Allowance (DLA) or Attendance Allowance (AA) under what the DWP calls "Special Rules." It is appropriate to complete the form if the patient's death can "reasonably be expected" within the next 6 months. This does not mean it must be more likely than not, simply that death within 6 months would not be unexpected. Once your doctor has issued a DS1500 you or your representative will need to contact social services and tell them you are applying under the special rules. They will send you the application form by return of post.

**Continuing care funding** - This is a package of care arranged and funded solely by the NHS. It is given when a patient's health needs are substantial. The care can be provided in a range of settings, including an NHS hospital, a care home or someone's own home. Assessment can be undertaken by any healthcare professional but most commonly by the integrated community care team working with social services. The process can be lengthy but can be "fasttracked" for patients with terminal illness.

**Carers Allowance** - The carers allowance is the main benefit for carers under 65 years old. If you are looking after someone for 35 hours a week or more, you may be eligible depending on your other work commitments.

#### **Certification after death -**

1. **Medical certificate of cause of death** - If the death is expected and the cause of death is known, this certificate can usually be issued by a doctor who has been looking after the patient. This certificate needs to be taken to the registrar of births and deaths and a formal death certificate will be issued. An appointment with the registrar will need to be arranged. It is usually a relative or close friend who attends this appointment.
2. **Death certificate** - The death certificate is a copy of the entry made by the registrar in the death register. This certificate is needed to deal with money or property left by the person who has died, including dealing with the will. You will be advised to get several official copies of this certificate.
3. **Cremation Certificate** - If the deceased is to be cremated a further certificate needs to be completed by two doctors. The first doctor usually will be the doctor who issued the death certificate, and the second will be an independent doctor who has been qualified for more than 5 years. Both doctors may want to discuss events around the death with family or close friends particularly if they were present at the time of death.

**Coroner** - An elected public officer whose principal duty is to inquire by an inquest into the cause of any death which there is reason to suppose is not due to natural causes or the cause of death is unclear. Deaths due to violence, neglect, industrial disease, an accident, suicide, and during or immediately after an operation must be referred to the coroner. If the patient has not been seen by a doctor within the 14 days before death, under DoLS (see below) or if the cause of death is unknown they must also be referred. The coroner will then issue the death certificate or given permission for the attending doctors to do so, this may delay the issue of the death certificate.

**DoLS** - The Deprivation of Liberty Safeguards (DoLS) were introduced in 2009. DoLS aim to prevent the unlawful detention of adults in hospitals and care settings who lack capacity to choose where they live and/or to consent to care and treatment. If the patient is under DoLS at the time of death they will need to be referred to the coroner. Often patients in residential and nursing homes will have a DoLS in place.

#### **Services**

**The Rowans Hospice** - The Rowans Hospice is in Purbrook and is a local charity which provides palliative care to patients and their families with terminal illness in Portsmouth and South East Hampshire.

**St Wilfrid's Hospice** - St Wilfred's Hospice is in Chichester and is a local charity which provides palliative care to patients and their families with terminal illness in the Chichester area.

**Hospice Day care service** - Day care service can help to provide for particular physical, social, emotional and spiritual needs, these can be addressed with patients and family, with access to a wide range of services including; psychological support, complementary therapies, physiotherapy, spiritual care and the social work team. Both local hospices offer this service.

**Community hospice care** - The majority of hospice care occurs in the community, this can occur in care homes, community hospitals and within the patient's home. This is provided by the hospice team which includes doctors, clinical nurse specialists, physiotherapists, occupations therapists and social workers. They liaise closely with your GP and district nurses. Both local hospices offer this service.

**Macmillan nurses** - Macmillan nurses are specialist palliative care nurses. They have completed specialist courses in pain and symptom management, and psychological support. Most of the nurses work in NHS hospitals, hospices or in the community, they are funded by the charity Macmillan.

**Marie Curie** - This a charity who provide support and care to patient with terminal illness. They provide support and advice over the phone and online, by their nurse specialists and through a number of hospices funded by the charity. Access to Marie Curie nursing for example for night sitting can be made through your district nurse team.

**Rosemary foundation** - The Rosemary Foundation is a charity providing a 'Hospice at Home' service in Petersfield and the surrounding towns and villages including Emsworth. This service offers practical help, nursing care, emotional and counselling support, together with day and night sitting service and trained nurses available 24 hours a day.

**ICCT (integrated community care team)**- The integrated care team provides care, support and advice to people over the age of 18 who have a long term condition and live in their own home or in residential and nursing homes. This service works closely with other health professionals and support services to provide holistic assessments, case management and co-ordination of patient care. This team developed from and includes the district nursing team.

**Social services** - Local social services (Havant or Chichester depending on postcode) provide advice and assessment around care needs, and may provide financial support for those who are eligible. This can be fast-tracked based on clinical needs (see above DS1500 and continuing care funding).

Havant social services - 0300 555 1386, <http://www3.hants.gov.uk/contactus/as-contacts.htm>

Chichester social services - 01243 642121, <https://www.westsussex.gov.uk/social-care-and-health/>

This is not a comprehensive list and we appreciate feedback and suggestions and how we could develop this resource.