**Information Buster for Patients and Carers**

Welcome to our information sheet about all things relating to ‘End of Life’ care and support. This information is by no means exhaustive and is offered as guidance only.

**End of Life Care (EOLC)** - involves treatment, **care** and support for people who are nearing the end of their life

**Palliative Care** - is the treatment, **care** and support for people with a life-limiting illness.

**Hospice Care** - aims to improve the quality of life and wellbeing of adults and children with a life-limiting or terminal condition. It helps people live as fully and as well as they can to the end of their lives. Hospices can vary in what they offer, for example some offer respite care when the carer is in crisis, symptoms control, complementary therapies and carer support.

**Macmillan Nurse** - provides advice, emotional support, pain and symptom management for people with palliative care needs through to end of life care. They support the person with life-limiting conditions, not just cancer, their family, and the nursesand doctors who are looking after them.

**Specialist Palliative Care Team** - healthcare professionals with a range of skills to help you manage your life-limiting illness. Your palliative care team works together to meet your physical, psychological, social, spiritual and cultural needs and also helps your family and carers. These teams are in hospitals and also visit patients at home or in care homes. Macmillan nurses are often based in Specialist Palliative Care Teams

**Physiotherapist** - Earlier on in a patients illness the physiotherapist can help people maintain their independence and quality of life. Even in the final stages of illness, physiotherapy has been proved to relieve pain and improve mobility.

**Occupational Therapist (OT)** - a health professional which enables people to participate in everyday life activities to the best of their ability despite their condition, illness progression, activity limitations or participation restrictions. In palliative care this premise does not change, as occupational therapists are skilled in enabling people to adapt to their changing ability levels, and helping people to continue living. Along with nurses, OTs can order equipment.

**District Nurses** – support the patient to remain at home, treat wounds, order equipment and offer emotional and physical support. District Nurses are often the first point of contact for patients and families out of hours and at weekends.

**Dietitian** - health care professionals who are trained to provide advice, support and counselling about diet, food and nutrition

**Speech and Language Therapist (SALT)** - provides treatment, support and care for patients who have difficulties with communication, eating, drinking and swallowing.

**Preferred Place of Death** – every person has an option to choose were they would like to die, this includes home, hospice, care home or hospital.

**Preferred Place of Care** – a person may want to be cared for at home but prefer to die elsewhere.

**Anticipatory Medication** – medication which is prescribed to be available to help with pain and symptoms in the last days of someone’s life.

**Continuing Health Care** - package of care for people who are assessed as having significant ongoing healthcare needs. This means care is arranged and funded by the NHS.

**Syringe Pump** - is a medical device that regulates the rate of drug administration through a **syringe**. A **syringe** **pump** is precise as it delivers medication slowly usually over a period of 24 hours. Nurses are responsible for setting these up.

**Mental Capacity** – being able to make your own decisions. Someone lacking capacity because of an illness or disability cannot do one or more of the following things:

Understand information given to them about a particular decision.

Retain that information long enough to be able to make the decision.

Weigh up the information available to make the decision.

Communicate their decision.

**Advance Care Planning** - is a process that enables individuals to make plans about their future health care. Advance care plans provide direction to healthcare professionals when a person is not in a position to make and/or communicate their own healthcare choices. Advance care planning is applicable to adults at all stages of life. Participation in advance care planning has been shown to reduce stress and anxiety for patients and their families, and lead to improvements in end of life care.

**Emergency Health Care Plans (EHCP)** - allow the patient’s views of their health care to be shared with health care providers, along with information about any common or recurring health problems.  As a result, patients receive the most appropriate care that they have helped to influence.

**Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)** - is a document issued and signed by a doctor or senior nurse, which tells your medical team not to attempt cardiopulmonary resuscitation (CPR). The form is designed to be easily recognised and verifiable, allowing healthcare professionals to make decisions quickly about how to treat you.

Depending on the Trust senior nurses can also write DNACPRs for patients. This is a 'medical' decision and does have to be discussed with the patient and where appropriate the family (with the patient’s agreement). A professional can complete the form as a best interests decision without discussing with the patient if they have substantial reason to believe that this will cause significant distress to the patient. This should be in exceptional circumstances. The form does not have to be signed by the patient or family. The form has a section to say that it has been discussed with the patient.

**Advance Decisions to refuse Treatment** (Also known as a Living Will or Advance Directive) - is a decision you can make now to refuse a specific type of treatment at some time in the future.

It lets your family, carers and health professionals know your wishes about refusing treatment if you are unable to make or communicate those decisions yourself.

The treatments you are deciding to refuse must all be named in the advance decision. You may want to refuse a treatment in some situations, but not others. If this is the case, you need to be clear about all the circumstances in which you want to refuse this treatment.

**Lasting Power of Attorney (Welfare / Finance)** - There are two types of Lasting Power of Attorney. One takes care of your assets and financial affairs – this is known as a [Lasting Power of Attorney for Property and Financial Affairs](http://ukcareguide.co.uk/lasting-power-attorney-property-financial-affairs/). The other type of Lasting Power of Attorney is a Lasting Power of Attorney for Health and Welfare.

This type of Lasting Power of Attorney enables a nominated family member or friend to make decisions on your behalf regarding your day-to-day care and wellbeing. These include:

Personal care and care provision (such as choosing a home care company or residential placement for you, arranging meals, enabling you to take part in social activities)

Medical care (your attorney may be asked to make decisions on your behalf regarding treatment)

**Palliative care** (your attorney may be asked to make a decision regarding life-saving treatment or end of life care)

**Who will support me?**

Your GP, community nursing team and specialist palliative care team can offer advice. For some patient and carers this will include the hospital cancer liaison services.

**Make a will**

Writing a will allows you to plan what happens to your money and possessions after you die. It is also a good way of letting people know any wishes you have about a funeral, or how you would like to be remembered. If you die without a will, your possessions will be allocated according to set rules, rather than according to your wishes.

There are several ways of getting yours written. From solicitors to do-it-yourself wills, choose what is right for you.

There are three main options to choose from:

use a solicitor

use a will writing service

do it yourself

For a will to be valid, you need to meet certain conditions. It is easy to make a mistake, so be sure you are familiar with the rules. **If in doubt speak to an expert.**

Dying Matters - www.dyingmatters.org

Citizens’ Advice Bureau - www.gov.uk/civil-legal-advice or 0345 345 4345

The Law Society - www.lawsociety.org.uk or 020 7242 1222

Office of the Public Guardian - www.publicguardian.gov.uk or 0300 456 0300

 **Make a funeral plan**

Have you ever thought about what you want for your funeral? You probably already know whether you want to be buried or cremated, but what about the details? Where do you want your funeral to be held? Do you want readings and, if so, which ones and read by whom? Perhaps there's even a particular route you would like your hearse to take.

Other useful sources of information and advice on organising a funeral include:

Age UK: www.ageuk.org.uk

NHS Choices: www.nhs.uk/CarersDirect/guide/bereavement/Pages/Arrangingafuneral.aspx

**Make sure your loved ones know your plans**

These conversations with your family and friends can be hard but consider talking to them, by sharing your thoughts and feelings about the future. If you have important documents or notes about your care, inheritance or funeral, keep them in a safe place and let loved ones know where they are. If the documents are hard to find your wishes may not be carried out.

Remember family and friends can be reluctant to have these conversation, they may be worried about saying the wrong things to you or do not want to think about your death.

**Sign up as an organ donor**

Other people can benefit from your organs after your death. If you want to find out more about organ donation contact NHS Blood and Transplant: www.organdonation.nhs.uk or

call 0300 123 2323.

**Additional Support**

**Marie Curie** - provide care and vital emotional support to people in their own homes. Marie Curie helps people living with any terminal illness and their families make the most of the time they have together by delivering expert hands-on care, emotional support, research and guidance. Call the Marie Curie Support Line for practical or clinical information and emotional support if you are living with or caring for someone who has a terminal illness, whatever your situation.

Marie Curie Support Line 0800 090 2309

**Macmillan Cancer Support** – From the moment you are diagnosed, through your treatment and beyond, Macmillan offering emotional, physical and financial support. Find out what to expect, get information, practical advice and support

Support line 0808 808 00 007 days a week, 8am-8pm

Website: www.macmillan.org.uk

**Dying Matters** is a coalition of 32,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

Telephone: 08000 21 44 66

Website: www.dyingmatters.org

**Scarborough & Whitby Carers Resources**

Tel. 01723 850155
Email: staff@carersresource.net

Website www.carersresource.net

**Hambleton & Richmondshire Carers Centre**

Support line open Mon-Fri 9 am – 5 pm

Tel 01609 780872

Email info@hrcarers.org.uk

Website: hrcarers.org.uk

**North Yorkshire Connect** – find community organisations that can provide help and advice at [www.northyorkshireconnect.org.uk](http://www.northyorkshireconnect.org.uk)

**Northern Cancer Alliance** - All care decisions must come from a shared partnership between the professional and patient. For those who do not have capacity for their choices, or may lose that capacity in the future it is important that the right choices are made. The link below is a resource for deciding rights.

www.northerncanceralliance.nhs.uk/deciding-right/

**Benefits**

**Attendance Allowance line** - You can call this government helpline to get support and information on Attendance Allowance.
Telephone 0800 731 0122

**Carer's Allowance Unit** - You can call this helpline number to get information and support on Carer's Allowance.
Telephone 0800 731 0297

**Disability Living Allowance** - You can call this number to get information and support on Disability Living Allowance.

Telephone 0800 121 4600

**Employment and Support Allowance/Universal Credit** - You can call this number to get information on Employment and Support Allowance. To start your claim for ESA by ringing the Job Centre Plus claim-line **0800 055 6688.**  For new style ESA queries, telephone: 0800 328 5644.

**Personal Independence Payment (PIP**) - is a benefit for people who may need help with daily activities or getting around because of a long-term illness or disability. PIP has two parts - a daily living component and a mobility component. PIP has replaced [Disability Living Allowance](https://www.ageuk.org.uk/information-advice/money-legal/benefits-entitlements/disability-living-allowance/) for anyone making a new claim. Department for Work and Pensions (DWP) on **0800 917 2222**

