Is the Palliative Care Record confidential?

Your Record is confidential and only professionals involved in your care, with your consent, may access your Palliative Care information. This Record will only be accessed when you need help or advice.

May I update my Record at any time for any reason?

During your care, your doctor or nurse will continue to consult with you about decisions relating to your care and you can make changes at any time.

It is essential that you inform your GP, Specialist Nurse or District Nurse if you change GP or move to a new address.

How can I access this information about me?

When your Record is created, you will be offered a paper copy. It is your choice whether or not you take a copy but you can request this at any time; just ask your nurse or doctor.

What will my information be used for?

Your Record will be used to note your care decisions and it may also be used to monitor NHS practice and to ensure the information in Palliative Care Records is of a high quality. If your information is used for this purpose, it will be anonymous to protect your confidentiality.

Patient Information Leaflet NWCSCN V1.4

Reviewed: June 2020

Where can I get more information?

Further information can be obtained from the Clinician looking after your care.

Name: ....

GP: ....

Tel: ....

Nurse: ....

Tel: ....

Your Own Notes:

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NHS
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Strategic Clinical Networks

Patient Information Leaflet

Supportive and Palliative Care Register and Electronic Palliative Care Coordinating System (EPaCCS)

This leaflet will provide you and those people important to you with information about your GP's **Supportive and Palliative Care Register.** The Register ensures that patients who are approaching the end of life are known to the appropriate multi-professional team.

With your consent, the information you provide will be included in an **Electronic Palliative Care Coordinating System**, commonly known as **EPaCCS**. The EPaCCS record highlights your special care needs to those caring for you and ensures your care is prioritised.

What is Palliative Care?

Palliative and supportive care aims to help you continue to live as well as possible right up to the end by managing your symptoms and any other problems including physical, psychological, social and spiritual needs.

Palliative Care:

- supports open and honest conversations about the progression of your illness, death and dying and Advance Care Planning;
- uses an holistic approach; this treats you as the whole person not just your illness or symptoms;
- provides relief from pain and other distressing symptoms;
- affirms life and considers dying a normal process;
- aims to support you but not hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers coordinated care and support you to live as well as possible right until the end of life;
- offers a support system to help families cope with the illness and the subsequent bereavement;
- uses a team approach to address your needs and those of your family and, if necessary, includes bereavement counselling;
- will enhance quality of life and may positively influence the course of illness;
- is applicable early in the course of your illness and in conjunction with other therapies.

What is Advance Care Planning?

Advance Care Planning starts with conversations that you, your loved ones and/or carers will have with the care professionals looking after you. These conversations should focus on you and include your wishes and preferences for your present and future care.

Many people have views on their care, such as how and where they would like to be cared for and treatments they would accept or like to avoid, such as resuscitation.

Recording your preferences is important as a way of ensuring that your wishes are followed at a time when you may not be able to speak for yourself.

The Care Professionals may need to ask some delicate questions but they will make every effort to discuss your care and wishes in a sensitive manner. However, if you find any of the questions upsetting, you do not need to answer. You can choose whether or not you want to participate in Advance Care Planning.

What is a Supportive and Palliative Care Register?

A Supportive and Palliative Care Register is a list held by your GP Surgery of those people under their care who may be approaching end of life. Once you have been assessed and included on the Register you will be able to discuss your wishes and preferences.

Your doctor or nurse will talk with you about your illness and wishes, and create a care plan with you. Regular meetings will be held by your GP and health and social care professionals to discuss your care. Updates to your wishes can be made during these meetings and at any other time.

What is a Palliative Care Record?

It is your personal record which is held securely by your GP. This may also be known as an Electronic Palliative Care Coordination System (EPaCCS).

Examples of the things that you may wish to discuss include:

- Your treatment choices;
- Managing your symptoms;
- Managing your diet and fluids;
- Where care should take place and where, when the time comes, you would wish to die;
- Decisions you have made about your care;
- Resuscitation status;
- Who you would like contacted and who you would like to make decisions on your behalf;
- Existence of Lasting Power of Attorney (LPA) for Health & Welfare.

If you wish, you can be given a copy of your palliative care record.

What are the benefits of sharing a Palliative Care Record?

Your Palliative Care Record highlights your special care needs and ensures that your wishes about your care are recorded, communicated to and prioritised by those caring for you.

Your consent is required for these details to be accessible to your GP, district nurses, hospital team, specialist nurses, the local hospice, the ambulance service and out-of-hours services. Access to this information will enable these professionals to understand your decisions and coordinate your care.

Your carers and next of kin should be informed that you have a Palliative Care Record so that everyone knows your wishes and can work together to help you.

What happens if I do not want to share my Palliative Care preferences and wishes?

Your consent is required to share your Palliative Care Record; it will never be shared without your permission. When you are asked for consent, it is your right to refuse and you can change your mind at any time. Should you decide to change your mind and withdraw consent, your record will be updated and access will be restricted.

Whatever your decision, you will receive the best possible care, but you should share your wishes with your family and those important to you.