



Blackpool Teaching Hospitals **NHS**  
NHS Foundation Trust

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**Blackpool**  
**Clinical Commissioning Group**

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**Fylde and Wyre**  
**Clinical Commissioning Group**



# No Decision About Me Without Me

## Your Palliative Care Record

### Patient Information Leaflet End of Life Care

#### Options available

If you'd like a large print, audio, Braille or a translated version of this leaflet then please call:

**01253 955588**

Our Four Values:

People Centred

Positive

Compassion

Excellence

**Your Palliative Care Record will be held on an electronic system known as Electronic Palliative Care Co-ordination System (EPaCCS)**

**EPaCCS ENSURES current information about your condition is available to professionals involved in your care, with your consent.**

### **What is Palliative Care?**

*'Palliative Care is an approach that improves 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 means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.*

World Health Organisation 2002

### **What is a Palliative Care Record?**

Most patients have their own views on how they would like to be cared for, especially when they are ill. This can include information regarding what you would like to happen if you cannot speak for yourself; where you would like to be cared for and treatments you would like to avoid.

A doctor or nurse will talk with you about your illness and wishes, and create a care plan that is available to help you. All these details will be entered into your palliative care record which will exist inside your secure electronic health record. This is a free NHS service.

This record will be accessible with your consent to your GP, community nurses, hospital team, specialist nurses, the local hospice, the ambulance service and out of hours services. If you need help, the doctors and nurses caring for you either in the community or in the hospital will be able to access the information about you to enable us to coordinate your care.

## **What are the benefits of sharing a Palliative Care Record?**

Your Palliative Care Record will give you an opportunity to have your decisions and expressed wishes about your care recorded. This information will be available to all professionals who are looking after you. The fact that everyone involved can see your care plan and wishes will help to ensure that any care you receive is in line with what you have decided. You have complete choice whether or not to participate.

## **What sort of information will be shared?**

The system will share information which will help support decisions regarding your care, including:

- Where you want to be cared for.
- Decisions you have made for your future care.
- Information for professionals delivering or coordinating your care, e.g. contact details for your main carer or contact, the key health worker, resuscitation wishes, etc.
- Where you wish to die if you chose to express this.

The information recorded is used to support your decisions and wishes, and to help staff and organisations to respect these.

## **Is the Palliative Care Record confidential?**

Yes, your record is confidential. Only professionals involved in your care and issued with a secure user name and password will be able to see your Palliative Care information. Your record will ONLY be accessed when you need help or advice.

In addition, it is a good idea to let your carers and next of kin know that you have a Palliative Care Record so that everyone you want to, knows your wishes about your care. That way everyone can work together to help you. To ensure that the information in the Palliative Care Record is of high quality, care and data managers employed by the NHS will be able to view your record for monitoring purposes only. They will have secure user names and passwords.

## **What happens if I agreed to share my details with other health professionals?**

We need your consent to share your record with other health professionals involved in your care (such as the ambulance service, out of hours GPs, hospices, hospitals, etc.). One of your care professionals, such as your GP, Specialist Nurse, District or Community Nurse, will:

- Have a discussion with you about your condition, and whether you have any particular views on your future care.
- Ask you if you consent to have your details on the Palliative Care Record shared with other health professionals involved in your care.

- If you say yes, they will input your details, including your age, address, next of kin, diagnosis and your specific wishes. They will also create a care plan to let other doctors and nurses know about your condition and what to do if a problem arises.

Some of the questions the care professionals may need to ask you could be sensitive. The nurse / doctor 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.

Once you have given consent, the system will, when necessary:

- Alert A&E staff and the Specialist Nurses if you are admitted to your local hospital to tell them that information about you is available if needed.
- Give care professionals access to your Palliative Care Record and provide you with a paper copy to check and keep. You do not have to take a copy.

### **What if I change my mind on any decisions?**

The clinician looking after you will discuss this with you and make any changes to the information held.

Throughout your care, staff will continue to consult with you about decisions relating to your care. You can make changes to your preferences and wishes at any time.

## **How can I access this information about me?**

When your entry is created, you will be offered a paper copy. It is up to you whether you take a copy or not. You can request this at any time. You just need to ask the nurse or doctor who discusses your Palliative Care Record with you to print you off a copy.

## **What will my information be used for?**

The recording and sharing of your information is crucial to ensuring good communication and coordination of care between your health professionals, which is the objective of the system.

Your data may also be used to ensure the NHS plans and service meet peoples' needs. If your information is used for this purpose, it will be anonymised to protect your confidentiality.

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

We need your consent to share your Palliative Care Record. It will never be shared without you being asked first. When you are asked, if you give your consent it is your right to refuse. You can change your mind at any time.

Should you decide to change your mind and withdraw consent, your record will be updated to reflect your decision and professionals will no longer be able to access your record.

Whatever you decide, everyone will still give you the best care possible with the information they have.

## **Are there any costs?**

No, there are no costs to you. This service is provided through the National Health Service.

## **What should I do if I want to update my record, for example, if I move or my wishes change?**

Your healthcare team will regularly discuss your health issues with you. If your wishes change at any time, they will update your Palliative Care Record. Please inform your GP, Specialist Nurse or District Nurse if you change GP or move to a new address.

## **Where can I get more information?**

If you require more information, you should contact the Clinician looking after your care.

## **Who should I tell?**

If you have included the names and contact details of people that you wish to be involved in decisions about your care, please let them know.



## Useful contact details

### Clinician Contact Details

This is the contact you should use if you need medical or nursing advice:

FCMS Care Co-ordination 01253 955750

With thanks to Central and Eastern Cheshire End of Life Care Team

Hospital Switchboard: **01253 300000**

### Patient Relations Department

The Patient Relations Department offer impartial advice and deal with any concerns or complaints the Trust receives. You can contact them via:

Tel: **01253 955589**

email: [patient.relations@bfwh.nhs.uk](mailto:patient.relations@bfwh.nhs.uk)

You can also write to us at:

**Patient Relations Department, Blackpool Victoria Hospital,  
Whinney Heys Road, Blackpool FY3 8NR**

Further information is available on our website: [www.bfwh.nhs.uk](http://www.bfwh.nhs.uk)

### References

This leaflet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this leaflet are available on request from: **Procedural Document and Leaflet Coordinator 01253 953397**

**Approved by:** ALTC Divisional Board  
**Date of Publication:** 23/09/2016  
**Reference No:** BTH470 - PL/1029 (v1)  
**Author:** EPaCC group  
**Review Date:** 01/09/2019

