Electronic Palliative Care Coordination System (EPaCCS) / Palliative Care Register

Information for patients
What is the Electronic Palliative Care Coordination System (EPaCCS) / Palliative Care Register?

Communication and coordination between health care professionals is key to providing high quality care for patients with life limiting and long term conditions. As a patient you may well have views about your care: what you would like to happen, where you want to receive care and even things you wish to avoid. This is known as Advance Care Planning (ACP). It may help to include your family and carers when making these plans. The Electronic Palliative Care Coordination System records and shares this information in an electronic record that can then be viewed by health care professionals.

How will this benefit me?

EPaCCS can be accessed by any professional who may be caring for you including GP, district nurses, specialist nurses, Macmillan nurses, hospices and some hospital services. It can be particularly useful for professionals such as out of hours doctors and night nursing services who are less familiar with you to know what type of care they should deliver to you.

Patients on EPaCCS form a register at your GP practice. Regular meetings called Gold Standards Framework (GSF) meetings allow the professionals involved in caring for you to meet together to help plan your care and if necessary to update any information on EPaCCS according to your wishes and preferences or changes in your condition. GSF is widely used throughout the country in many different settings to enable people to receive a ‘gold standard’ of care and to help them live well until they die.

You will be given a ‘Green Card’ which you or your carers can show to health care professionals so that they know that they can access information about you on EPaCCS. The card will also contain useful contact details for those involved in your care.
Do you need my permission to include my details on EPaCCS?

You will be asked by one of the health care professionals caring for you for permission to include your details on EPaCCS and for consent to share this information with other professionals looking after you.

What sort of information will be shared?

EPaCCS will record:

- Your diagnosis
- What medications you are prescribed
- Where you would prefer to be cared for
- Decisions you have made about your care, including resuscitation
- Next of kin details and who you would wish to speak for you if you are unable to make decisions in the future

Your health care team will regularly discuss your condition with you and update your EPaCCS record if your condition or wishes change.

Who will have access to my information?

Your information will be held securely on a computer system and will be available only to the health care professionals caring for you. The information may also be used to help plan the best services in the future. If it is used in this way it will be made anonymous.

What happens if I do not want to have an EPaCCS record?

You will not be included without being asked first. You can change your mind at any time. Let one of your health care professionals know and they will close down your record so that professionals can no longer access your record. Whatever you decide everyone will still give you the best care possible with the information they have but the added benefit of the coordination and communication provided by EPaCCS may be lost.
Useful contact numbers:

District Nurse:
- Wakefield / Pontefract: 01924 327591
- Kirklees: 01484 221600

When your GP surgery is closed if you need a doctor: 03456 050621

Specialist Palliative Care Team:

**Wakefield / Pontefract:**
Mid Yorkshire Macmillan Specialist Palliative Care Team: 01924 543801

**Kirklees**
Kirkwood Hospice Community Specialist Palliative Care Team: 01484 557900

24 hour telephone advice is available to patients and healthcare professionals from the following hospices:
- Prince of Wales Hospice (Pontefract): 01977 708868
- Wakefield Hospice: 01924 331400
- Kirkwood Hospice (Huddersfield): 01484 557900

We are committed to providing high quality care. If you have a suggestion, comment, complaint or appreciation about the care you have received, or if you need this leaflet in another format please contact the Patient Advice and Liaison Service on: 01924 542972 or email: **pals@midyorks.nhs.uk**

To contact any of our hospitals call: **0844 811 8110**
To book or change an appointment call: 0844 822 0022

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