

Pilgrims Hospice Data Sharing information for Patient

Whole Record Sharing

Electronic healthcare records (including your GP notes) are held by your registered GP. More recently, with advances in IT, these records can now be accessed, either partially or fully, by various providers of medical care e.g. hospitals, 111, hospices. This has clear benefits in providing continuity of care. It is particularly helpful when medical input is required out-of-hours, by making available a detailed and up to date history with all the relevant background information. This is particularly of value in an emergency, or perhaps when a person is too ill to give a history or express their wishes. In situations where a patient is unconscious, very ill, and/or receiving life-saving emergency treatment, medical records can be shared without explicit consent from the patient to do so. This is on the basis that, at that moment in time, it is in a patient's best interest to share the specific data relevant to their healthcare.

Historically, when a patient was referred to a health care provider (outside of an emergency and outside of the surgery e.g. to a hospital specialist), a letter was written containing all the relevant information. This included a brief summary of significant medical problems, medications and allergies. The information was limited to what was thought relevant and important in the context of the specific referral.

Now, however, a referral to Pilgrim's Hospices includes the option to share your health record (your whole electronic GP record) with the hospice clinical team who will be involved in your care. This means that notes from consultations you have had with your GP (historical and up until the present time), or with the medical team at Pilgrim's Hospice, can be seen immediately by everyone involved in your care (hospice or GP based).

The clinician accessing your notes at any point in time will be able to see what care has been provided so far, communicate regarding medication changes, and provide the means for timely requests or referrals to be completed. Furthermore, should you need urgent care or out of hours, the Pilgrim's Hospices clinicians will have all the information they require to make informed appropriate treatment decisions.

In order to make someone's entire GP medical record accessible to another organisation, we require your explicit consent. For most people, this will not raise any concerns. However, if you have information on your medical records that you do not wish to be shared, you can decide to opt-out of this type of 'whole electronic GP record' sharing. If you do not want your whole record shared, other more restrictive options to share information are also available.

To summarize:

- We believe that sharing your whole medical record in real-time with Pilgrim's Hospice will enhance your medical care and allow both Pilgrim's and Ivy Court Surgery to deliver a safer, more effective and more responsive service.
- Notes on particularly sensitive diagnoses, conversations or problems are excluded from record sharing. A list of these is available if relevant.
- You can discuss any concerns about 'whole record sharing' with your GP, the Practice Manager or the Caldicott Guardian at the surgery
- You are able to opt-out of non-emergency 'whole record sharing' if it is of concern to you. Importantly it does not affect the timing of, or access to good palliative care as provided by GPs or Hospice staff.