

If you would like to know more about the information in this leaflet, please ask a member of staff

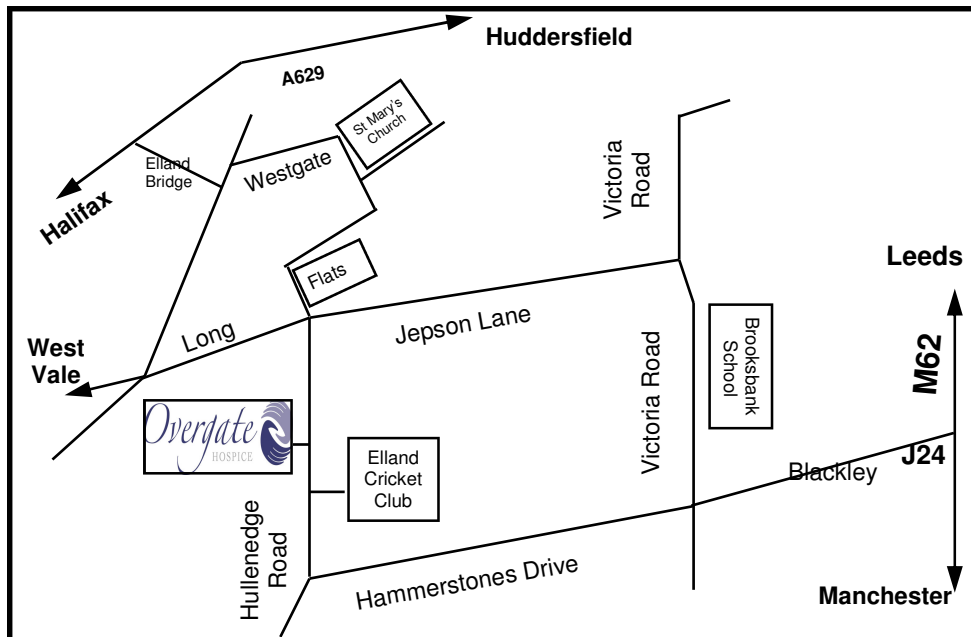
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Research at Overgate Hospice

Information for patients and carers



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What does the Hospice do to ensure that the research conducted here is necessary and patients are protected?

Before any patients are approached to take part in a research study at Overgate Hospice, the study will have had to have been approved by the hospice's Clinical Sub-Committee and Local Research Ethics Committee. Both committees will check to see if they are happy that the study meets local and national standards for the conduct of research.

If you would like to ask any further questions about a specific research study, the kind of research undertaken within the hospice or this leaflet please do not hesitate to contact the Medical Team

Why do we do research?

At Overgate Hospice we undertake research to expand knowledge about the best ways of providing care for our patients.

Are there many research studies?

Doctors, nurses and other professionals sometimes want to conduct their research here.

Who will approach you to be in a research study?

You may be asked by a doctor, nurse or by an independent researcher to be involved in a research study. The person may be someone you have not seen before as part of your care, but will be introduced to you by someone you are familiar with.

What will the study involve?

Every research study is different. Before you can make a decision about whether you want to be in a research study or not, you must be told exactly what being in the study will involve.

The researcher will give you an information sheet for you to read before making a decision. The sheet should:

- Have the name of the study at the top.
- Explain why the study is being done
- Explain what the study involves.
- Give the name of a person for you to contact about the study.

The researcher will discuss the information sheet with you and ask you if you have any questions.

How will being in a study affect your care?

Every research study is different. It may involve you taking extra tablets. It may involve you talking about your experiences. It should not alter any other aspect of your care at the Hospice.

Who can you speak to if you are unsure about any aspect of a research study?

You will be given the name and telephone number of a person you can talk to if you are unsure about anything on the research study information sheet. The named person should be able to answer any questions you may have at any stage of the research.

What happens if you don't want to be part of a research study?

If you don't want to take part in a research study, just say no! It will not affect the standard of care you receive at Overgate Hospice in any way, either now or in the future.

What happens if you change your mind about being in a research study?

You are free to change your mind about being in a study at any time. You do not have to give a reason why you have changed your mind and it will not affect the care you receive now or in the future.

What is the involvement of my family doctor?

We encourage you to discuss your participation in a study with your doctor(s). When you enter into a study, you may be asked to sign a medical release form so that your medical information may be shared between your family doctor and the researcher. This information will help to provide for more comprehensive care and allows for medication outside of the study to be prescribed by your family doctor if necessary.

Making the decision

It is important that you are well informed and feel confident and secure about participating.

Before deciding to participate, you should talk with your own doctors, family members and clinical staff. Be sure you know the answers to the following questions before you make a decision:

- What is the purpose of the study?
- What is required of me?
- What is my role in the study
- Will the study directly benefit me?
- Will the study benefit others?
- Are there any risks? If so, what are they and what are the chances that they will occur?
- What discomforts are involved?
- How will my care differ if I am part of the research study?
- Will the research involve any additional tests and if so, how many and for how long?
- What, if any, equipment will be fitted to me?
- Will I have to take any extra tablets or have more injections or blood tests?
- What is the total time involved?
- Are there other inconveniences?
- Have I discussed participation in the study with those who are important to me, such as family and friends?
- Do I wish to participate in this study?