



UNDERSTANDING YOUR CARE



KILBRYDE HOSPICE

Information for Patients, Families & Carers

You Matter!

If you are living with a life-limiting illness, your personal goals and the things that are important to you should form the basis of your care. The people who matter most in your life should also have the opportunity to be involved in the way you choose. Kilbryde Hospice is keen to encourage and support significant conversations between patients, their families and carers.

What is medical treatment?

Medical treatment is defined as any procedure or treatment designed to safeguard physical or mental health. This includes fundamental aspects of care such as nutrition and hygiene as well as specific treatments for illnesses or conditions. Providing treatment against the wishes of a person capable of agreeing to treatment violates the principle of patient autonomy and can constitute assault. Autonomy requires the capacity to think and make decisions consistent with one's own values and the ability to act freely without undue influence from others.

People have right to choose what happens to their own bodies, and healthcare professionals must respect that right. Therefore, people must give valid consent to all forms of healthcare whether this is personal care or major surgery.

This right to self-determination in a capable adult extends to refusing to undergo any medical intervention, even where this may result in harm or even death.

In an emergency situation, healthcare professionals may provide treatment to patients without consent, provided that the treatment is necessary to preserve life or to prevent a serious deterioration in their condition. Accurate and detailed recording of both the decision and the decision-making process is essential.

What does this mean?

Before any doctor, nurse or therapist examines or treats you, they must seek your permission or 'consent' to do so. This could simply mean following their suggestions, such as your GP asking to have a look at your throat and you showing your consent by opening your mouth. Sometimes they will ask you to sign a form, depending on the seriousness of what they're proposing or whether it carries risks as well as benefits.

It does not matter so much how you show your consent: whether you sign or say you agree. What is important is that your consent is genuine or valid and that you understand what is. You must be able to give your consent

- you must be given enough information to enable you to make a decision
- you must be acting under your own free will and not, for example, under the strong influence of another person.

The Law assumes that if you are an adult you are able to make your own decisions, unless it's proved otherwise. As long as you can understand and weigh up the information needed to make the decision, you should be able to make it.

What if I'm not able to take a particular decision?

If you become too ill to make or express your views, people providing health care can still give you treatment that they believe is in your best interests. The only exception is if you have clearly refused a particular treatment in advance.

No-one (not even husbands, wives, partners or close relatives) can give consent to treatment on behalf of another adult unless they have been given that authority by a Power of Attorney that has been registered. However, friends and relatives may have useful advice to give. They may be able to tell healthcare professionals about the person's beliefs and values – for example whether they have accepted or refused certain kinds of treatment in the past or have strong views on some health questions. So it is important to discuss your views with your friends and relatives.

What if I'm asked about students being present?

Occasionally you may be asked if you mind students being present while you are treated. If you are undecided, ask what they intend doing – just observing, taking notes or examining you. If you prefer, you can specify students of one sex only. If you are not comfortable about students being present, you can always say no. It will not make any difference to the quality of the care you receive.

What sort of information do I need?

In order to make a decision, you need to have information from health professionals about the treatment or investigation which is being offered to you. You should always ask them more questions if you don't understand or if you want more information. For example:

- What sort of things will the treatment involve?
- What are the benefits they hope will result?
- How good are the chances of getting such benefits?
- Are there any alternatives?
- What are the risks, if any?
- If there are risks, are they minor or serious?
- What may happen if you don't have treatment?

How much time can I take to decide?

Your doctor, nurse or therapist may certainly encourage you to accept a particular treatment if they believe it will be helpful for you, but it is your decision whether or not to go ahead. If you want more time to think about your decision, say so.

Can I refuse treatment in advance?

You may be quite certain that you would not want a particular treatment in the future. In that case you may like to make a written record of your wishes (an Anticipatory Care Plan) and make sure people close to you know. Then if this situation arises at some point in the future and you are not in a position to tell your wishes to people providing health care, they will be bound by your earlier decision.

It is important to be very precise about any treatment you are refusing in advance; otherwise you could exclude treatments which you would want to accept. For this reason it is advisable to seek medical advice about what treatments you are thinking of mentioning. It is also important to let people close to you know if you have changed your mind so they can pass on this information if necessary.

Can I say in advance which treatment I'd prefer?

You may want to write down the sorts of treatment you would rather have. You cannot insist on a particular kind of treatment, including cardiopulmonary resuscitation, if a health care professional does not believe it is right for you. However if the time ever comes when you can no longer make decisions or tell people about them, it would help people providing health care to have your wishes as a guide when deciding what is in your best interests.

You cannot request something that is against the law, such as euthanasia.

What if I'm asked to take part in research?

This may be as part of your treatment, for example to compare two different treatments; or it may be quite separate, for example being asked to provide extra blood samples for a research project. In any case, a research project will always be approved by a Research Ethics Committee before you are asked to take part in it.

It is for you to decide whether or not to take part. You should usually be given an information sheet about the research project, and you should ask as many additional questions as you want before coming to a decision. If you choose not to take part, this ought not to affect the rest of your care. If you agree to take part in a research project, and then change your mind, you are free to withdraw at any time.

Suppose I'm not happy about how I've been approached about consent?

Please tell your hospice doctor, nurse or therapist that you're worried. They will listen to your concerns and explain further. Conversely if you have serious concerns you can complain to Kilbryde Hospice about your treatment.

Please use these pages to make a note of any concerns you make have about your treatments. Feel free to discuss these with your Healthcare Professional

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About Kilbryde Hospice

Kilbryde Hospice is a voluntary independent hospice which exists to provide specialist palliative care to patients with life limiting progressive illnesses and to their relatives and carers. Services provided by Kilbryde Hospice are available to those people with palliative care needs. The service is provided free and does not discriminate on the basis of race, colour, faith, national origin, disability, sexual orientation, age or financial means.

We would like to hear from you!

We take all compliments, comments and complaints about our service seriously and deal with them in confidence. Kilbryde Hospice welcomes feedback on any of our services which can be submitted by post, or on our website.

www.kilbrydehospice.org.uk or by Email: info@kilbrydehospice.org.uk

Contact Us

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Registered Scottish Charity No. 032424
Registered Company No. SC224366

Should you feel that your complaint has not been resolved by Kilbryde Hospice, you may contact Healthcare Improvement Scotland regarding services delivered within Kilbryde Hospice or within a person's own home.

Healthcare Improvement Scotland, Gyle Square, 1 South Gyle Crescent, Edinburgh EH12 9EB, Telephone 0131 623 4300
www.healthcareimprovementscotland.org

Kilbryde Hospice aims to communicate effectively with all patients and carers. This document is available in braille format for those who are visually impaired. A translated version is also available for those whose first language is not English.

To facilitate this service, please call 01355 202020, or Email your request to info@kilbrydehospice.org.uk