

Living Wills Policy

Document Details		
Title	Living Wills	
Main points	Regarding the terminally ill and their options	
Who is the document aimed at?	All staff	
Author		
Approval process		
Approved by (Clinician/Manager)	EMT	
Most recent approval date	December 2021	
Category	Clinical	
Sub Category	End of Life	
Next review date	January 2024	
Distribution		
Who the policy will be distributed to	All staff	
Document Links		
Required by CQC		
Other		
Amendments History		
No	Date	Amendment
1		
2		
3		
4		
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Background

Hope Citadel strongly supports the principal of advance directives commonly known as Living Wills. Through advance directives patients have the legal right to make choices regarding medical treatment should they suffer loss of mental capacity in the future and to decline specific treatment, including life prolonging treatment. Where valid and applicable advance directives must be followed.

Advance directives/advance decisions (Living Wills / Refusals)

An advance directive (Living Will) is a mechanism whereby competent people give clear instructions about what is to be done if they subsequently lose the capacity to decide or to communicate. An advance directive is intended to be a binding refusal of treatment. Withholding or withdrawing treatment in the future made by an informed competent adult in contemplation of the specific circumstances which arise. It is legally binding.

Policy Statement

This policy aims to ensure that wherever possible patients in receipt of care from Hope Citadel staff have their expressed wishes and legal rights that are contained in advance directives respected and upheld where valid and applicable, the care given will be in the best interests of individual patients at all times

Responsibilities

It is the responsibility of all staff to familiarise themselves with this Policy.

Reception Staff/Admin staff

If any reception/admin staff are contacted by a patient in relation to advanced directives in any capacity, they will contact the Lead GP at the said site who will advise accordingly regarding an appropriate course of action such as an appointment with the patients GP of choice. Where the Lead GP is not available, they will contact a regular GP instead.

General Practitioners

- GPs can only act on an advance directive if it is brought to their attention. Under no circumstances should any delay or deviation to normal medical management occur whilst the document is being located.
- GPs are under no duty to undertake searches specifically for advance directive documentation. It is solely the burden of the patient that the directive has been brought to the attention of the medical professionals.
- The validity of an advance directive should be considered by treating clinicians.
- GPs must also ensure that the clinical situation in question has actually arisen. The directive must accurately reflect the clinical circumstances in which it is to be applied. Often there is no difficulty, however, where there is reasonable doubt that the conditions of the directive apply to the clinical circumstances in hand, it is better for staff to proceed as they would have in the absence of the directive. The Courts are most unlikely to criticise staff in this situation.
- GPs must take note of an advance directive and having been notified that an advance directive exists should make all reasonable efforts to acquaint themselves with its content. In cases of emergency however, necessary treatment should not normally be delayed whilst looking for an advance directive. If a person is now incapacitated but is known to have objections to all or some of the treatment, healthcare professionals may not be justified in proceeding even in an emergency. They will need to consider the available evidence about the patient's views and how convincing it seems. In the absence of evidence of refusal, treatment which is in the interests of that individual can be given.

- Questions arise about the ethical status of discontinuing treatment, which was already initiated prior to the discovery of an advance directive. The BMA considers that late discovery of an Advance Directive after treatment has been initiated does not mean that the directive cannot be implemented. Treatment should therefore be discontinued in accordance with the directive once it is known unless there is doubt as to the document's validity.
- GPs should consider their own views and inform patients at the outset of any absolute objection to the principle of the advance directive. The patient then has the opportunity to consult another doctor. Doctors who are unexpectedly faced with an advance directive who feel unable to comply should relinquish the patient's management to colleagues. However, if there is no other doctor available, there is a legal duty to comply with an appropriate and valid advance directive. Clinicians may be legally liable if they disregard the terms of a valid advance directive (i.e. refusal of treatment), if the directive is known of, and applicable to the circumstances.
- GPs following the terms of a clear advance directive and exercising due care and attention are unlikely to face any legal objections. However, basic care (measures necessary to keep a patient comfortable) should be given.
- GPs must always act with due care and attention. The mistaken application of an advance directive to a patient other than the one who made it would raise issues of negligence.
- If the situation is not identical to that described in the advance directive, it is still possible to act, if possible, in the general spirit of the directive. If any individuals are named in the directive for contact, they as well as the patient's GP may be able to clarify the patient's wishes.
- If there is doubt as to what a patient intended, the law supports a presumption that appropriate life prolonging measures and treatment should be given. GPs must use their own professional judgement about the appropriateness of the advance directive.
- If an advance directive is not applicable to the circumstances it is not legally binding, although it may give a valuable indication of the general treatment options the patient would prefer.
- An advance directive cannot demand that treatment is provided. Therefore, if an advance directive does consent to certain treatment options, the health team will have to assess whether the treatment is medically appropriate or advisable for the patient at that time.
- GPs faced with questions from their patients about advance directives or who are required to consider the implementation of an advance directive should consult the BMA's Code of Practice 1995 as well as this policy document. Staff should also be aware of the Mental Capacity Act 2005 and the impact that this has.
- Requests for further information by medical professionals which cannot be obtained from the CCG should be directed to:

Medical Ethics Committee Secretariat
Medical Ethics Department
BMA House
Tavistock Square
London, WC2H 9JP
Tel: 020 7383 6286

- GPs should be reminded that the provision of the Mental Capacity Act 2005 took full effect from 1 October 2007 and that there are changes to this area of practice both from a legal and clinical perspective. The law as it applies from 1 October 2007.

Nurses

- Please refer to NMC Code of Professional Conduct (2001). This states that when patients or clients no longer have capacity to consent or refuse treatment nurses must try to establish if previously indicated treatment preferences in an advance directive are still valid and must respect any refusal of treatment or care outlined when the individual was “legally competent, provided that the decision is clearly applicable to the present circumstances and that there is no reason to believe that they have changed their minds.” (NMC Code of Professional Conduct 2001 p 5)
- Nurses with a conscientious objection to limiting treatment at a patient’s request should make their views known via their line manager. The Hope Citadel Medical Directorate will endeavour to respect their beliefs and pass the management of the patient to a colleague. However, if delegation is impossible the NMC’s view is that nurses cannot refuse to care for patients in these circumstances. If this difficult situation arose, then the staff member would be supported by their line manager and provided with appropriate clinical supervision.

Legal Status

Where an informed, competent person has made an anticipatory choice, which is “clearly established and applicable in the circumstances”, doctors are bound by it. (BMA 1995).

Advance refusal of treatment, which is valid and applicable to subsequent circumstances in which the patient later lacks capacity is legally binding. An advanced refusal is valid if made voluntarily by an appropriately informed person. Failure to respect such an advanced refusal can result in legal action against the practitioner (DOH 2001). Advance directives/decisions are advance refusals of treatment.

A valid and applicable advance refusal is a legal document and as such must never be overridden or ignored by health professionals on the grounds of the professional’s personal conscientious objection to such a refusal (DOH 2001).

Patients are not able to refuse “basic care” and hygiene through an advance directive although they can legally refuse specific medical procedures. Basic care means those procedures which are essential to keep an individual comfortable.

The administration of medicine or the performance of any procedure which is solely or primarily designed to provide comfort to the patient or alleviate that person’s pain or symptoms of distress are elements of basic care. It is generally accepted that “basic care” includes warmth, shelter, pain relief, management of distressing symptoms such as vomiting and hygiene measures. However, nutrition and hydration should not be given to a person who indicates opposition and invasive measures such as tube feeding should not be instituted contrary to a clear advance refusal/directive. Individuals cannot make legally enforceable demands about specific treatments they wish to receive Health Care providers cannot be required to act contrary to the law and so a current or advance request for active euthanasia would be invalid.

Mental Health

A patient detained under the Mental Health Act 1983 can make an advance directive if they are competent at the time of making the particular decision. However, advance directives can be overridden by the provisions in Sections 58, 62 and 63 of the Mental Health Act 1983. In these particular circumstances patient consent is not

required by the Act and therefore the advance directive will not be applicable. However, if possible, a patient's advance directive or preferences should be considered as part of the treatment plan.

Verbal Advance Directives/Decisions

While a witnessed verbal advance directive of a clear refusal of treatment by an adult does have legal force, by contrast general statements of preferences should be respected, if appropriate, but are not legally binding. However, whilst a witnessed verbal refusal of treatment is an acceptable type of advance directive this directive should be made to a clinician wherever possible who should make a comprehensive record. A copy of that record should be kept in the patient's file. If a verbal advance directive has been made to a patient's relative or friend, it must be supported by appropriate evidence to be valid. The treating health professional should be happy that this evidence is satisfactory. From 1 October 2007 where an advance decision is to apply to life sustaining treatment it must be verified by a written statement to that effect signed and witnessed.

Children and young people

Advance directives are not legal for children and young people under 18. Similarly, the Mental Capacity Act 2005 does not apply to individuals under the age of 18. People who understand the implications of their choices can state in advance how they wish to be treated if they suffer loss of mental capacity. Young people under the age of 18 are entitled to have their views considered and these should be accommodated if possible. It is widely recognised that medical decisions relating to children should be a partnership involving patients, their families, and the healthcare team. However, the refusal of treatment by a young person is not necessarily binding on doctors and can be overridden by persons with parental responsibility or, if necessary, the court. An advance directive must be made by an adult in order to have legal effect. The European Court of Human Rights has taken the view that parents have the right under Article 8 of the European Convention to be involved in important decisions concerning their children.

Pregnant women

An advance directive will only apply where the woman has explicitly referred to the fact that the refusal should continue to apply despite her pregnancy and following the advance directive will not endanger a viable foetus. However, if an incapacitated pregnant woman presents with an apparently valid advance directive, then legal advice should be sought to clarify the position. The courts may consider the advance directive ineffective if withholding treatment risks the life of a viable foetus (BMA, 1995). An application to court can be made in these circumstances.

Assessment of Mental Capacity

Adults are presumed to have capacity but where doubt exists the health professional should seek appropriate assessment of the capacity of the patient to make the decision in question (DOH, 2001). An apparent lack of capacity to give or withhold consent to explore end of life issues may in fact be the result of communication difficulties rather than genuine incapacity. Appropriate colleagues should be involved in making assessments of capacity such as specialist learning difficulties teams, speech and language therapists, other specialists as required, unless the urgency of the patient's situation prevents this. If at all possible, the patient should be assisted to make and communicate their own decision, for example by providing information in non-verbal ways where appropriate. Those requiring information in another format or assistance of an advocate should be given information or assistance in obtaining this.

Note: The degree of capacity needed to make a decision will vary with the circumstances - in other words, a person may have the capacity needed to make certain decisions but not others. The level of understanding required to make decisions must be commensurate with the gravity of the decision being made.

In a legal context, a person is deemed to have capacity if they can understand and retain the information relevant to the decision in question, can believe that information, and can assess it to arrive at a choice. In order for the advance directive to be valid a patient must at the time it was made have had the capacity to understand and weigh the implications and consequences of that choice. As stated, the level of understanding must be commensurate with the gravity of the decision being made. The Mental Capacity Act 2005 also codifies the assessment of capacity. When assessing capacity, the starting position should be that an individual does indeed have it. Under the Act consider: -

Is there an impairment of, or disturbance in, the functioning of the person's mind or brain?

Does the impairment make the person unable to make the decision? Can the person: -

- understand the information relevant to that decision?
- retain that information?
- use or weigh that information as part of the process of making the decision?
- communicate their decision?

Try different ways of communicating and consider using professionals with specialist skills.

Where doubt continues to exist about a patient's mental capacity, the correct person to make the decision is a Judge and an application to court should be made for this purpose. All assessments of capacity should be recorded in the health professional's records. If the incapacity is temporary because of anaesthesia, sedation, intoxication or temporary unconsciousness, health professionals should not proceed beyond what is essential to preserve the patient's life or prevent deterioration in health.

Patients wishing to make an advance directive

When responding to requests for assistance with advance directives, GPs should consider:

- Is the patient over 18 years of age?
- Is the patient mentally competent? (In accordance with the Mental Capacity act 2005 –see above).
- Is it clear that the patient is reflecting his/her own views and is not being influenced by others.
- If there is a known illness does the patient have sufficient knowledge of the medical condition and possible treatment options?
- Has the patient discussed the specific conditions of their advance directive with a GP or other health professional?
- Does the patient know and understand the risks of not having treatment?

1. Individuals seeking advice must be given the Hope Citadel Patient Information Leaflet on Advance directives (Appendix 1). Those who require information in another format or assistance of an advocate should be assisted accordingly.

2. Patients should be encouraged to discuss their intention to make an advance directive with GP and also with their family, close friends and relevant other health and social care professionals. The matter should be fully discussed in the presence of a witness. Detailed contemporaneous notes of the matter discussed should be

made and a copy retained on the patients' medical record. The original note must be retained securely. The note should be legible, unambiguous, and not contain any abbreviations. The note should be clearly signed by the author and witnessed. It should be dated, and a note made of the time of the discussion and the circumstances whenever possible.

3. Those patients who have made Advance Directives should be encouraged to review and update it at least every 5 years (minimum).

Making a living will

Drafting an advance directive is the patient's responsibility. It is recommended that this be undertaken with advice and counselling as part of a continuing health professional-patient dialogue.

GPs consulted by patients wishing to make advance directives should take all reasonable steps to provide accurate factual information about treatment options and their implications and provide the patient with the Hope Citadel Advance Directive Patient Information Leaflet. If the patient wishes to then produce an advance directive and require assistance writing one the leaflet provides advice on advocacy organisations that can help. Under no circumstances should a GP assist in drafting a patient's advance directive.

Storage & notification of an advance directive

The storage of documentation regarding an advance directive and notification of its existence is the responsibility of the individual patient.

GPs /health professional will not incur liability if proceeding with medical treatment they did not know of or could not find the advanced directive although they will need to consider available evidence about the patients views.

Those close to a patient should be made aware of the existence of an Advance Directive, where it is stored, and where appropriate informed who the Health Care Proxy is. Some patients carry a card or bracelet indicating the existence and location of an advance directive.

Although not a legal requirement patients should be advised that a copy of the advance directive is lodged with their GP if possible and acceptable to the patient as this will allow the GP to provide information regarding the advance directive to other health professionals on referral or in emergency situations to provide information on request. A hard copy should be kept with the Lloyd George records and the existence of the advance directive clearly marked on these records. An electronic copy should be kept on the electronic records and an alert on the electronic records be created.

Patients should be encouraged to also lodged a copy of their advanced directive in their hospital records if they are treated for a prolong period by a specialist team.

Disputes

In the event of a disagreement between health professionals or between relatives about the patient's previously expressed wishes, opinions should be sought from relevant colleagues and others who are familiar with the patient. In the interim the patient should be treated in their best interests under the common law doctrine of necessity (now codified in Section 5 of the Mental Capacity Act 2005) until such issues are resolved. If the dispute cannot be resolved following these measures, then legal advice should be sought. All staff involved in a patient's care should have the opportunity of presenting their views. This includes community staff who may have known the patient over a longer period. Views of family members and close friends of the patient should also be

considered. Ultimately, the senior professional managing the particular episode of the patient's care must consider the available evidence of the patient's wishes before reaching a decision on issues raised by the advance directive, but they may need to seek advice from the courts if the matter cannot be resolved. In cases of dispute emergency treatment should be given until resolution (BMA 1995).

Withdrawal of an amendment of an advance directive

If a person wishes to withdraw their advance directive, they should destroy their copy and inform their GP and everyone else who has a copy or knows of its existence that it is no longer valid. If a health professional is informed by the author of an advance directive that it is being withdrawn the health professional is responsible for recording this in the clinical record including the date, time and circumstances. It is important to meet with the individual to discuss the required issues and changes. Any advance directive is superseded by a further clear and competent decision to this effect by the individual concerned whether written or verbal. Any copies held should be destroyed with the date and time of the destruction noted.

Where an advance directive no longer reflects a competent person's wishes it becomes invalid. Ideally where there are changes to an advance directive a new document should be produced and the old document destroyed. However, if an advance directive is to be altered, any alteration should be dated and signed with an independent witness. Holders of any copies should be alerted to the fact that the original has been amended and given a copy of the amended document. If a copy is held by any health professional it is the responsibility of the author to ensure that they are aware of the alterations and that an altered copy is available. The procedure for destruction of the original should then be followed. Photocopying of advance directives should not be undertaken by health professionals because of the difficulties in keeping a record of copies that may later need to be amended or destroyed.

Adults have the right under common law to refuse medical treatment in the absence of a formal Advance Directive. If a patient no longer has capacity and has not clearly indicated their wishes in the past, the decision to provide or withhold life prolonging treatment must be based on an assessment of their best interests.

Appendix 1 – Information Leaflet

Where can I get more information? Several health and social care related organizations provide these forms including:

Age Concern

Email: age@concernbnes.freemove.co.uk // Website: www.ageconcern.org.uk and then click on 'Information & Advice'

Alzheimer's Society

Gordon House, 10 Greencoat Place, London SW1P 1PH Helpline 0845 300 0336

website www.alzheimers.org.uk produces a free information sheet and guidance on preparing an advance directive – *Future medical treatment: advance statements and advanced directives or living wills*. This information sheet together with a sample advance directive form can also be downloaded as a pdf file from their website.

Patients Association

website: www.patients-association.com produces a booklet: *Living Wills – a guide for patients*. This booklet is free to download as a pdf file from their website.

What is An Advance Decision or Living Will? A practical way of planning ahead to ensure that a person's wishes are respected at a time when they are no longer capable of making decisions or conveying their wishes about treatment.

The Law and Living Wills A general principle of law and medical practice is that all adults have a right to consent to treatment or to refuse medical treatment.

You can nominate someone who should be consulted at the time a decision has to be made. The views expressed by that person will be considered by medical professionals although do not have legal force. Under the Mental Capacity Act 2005 you can nominate a person to take healthcare decisions on your behalf under a Lasting Power of Attorney. An advance directive/decision will still be valid however unless the Lasting Power of Attorney was created after the advance decision, and is valid/applicable in the circumstances. The views of a person appointed under a Lasting Power of Attorney with regard to healthcare decisions will have legal effect. People under 18 are entitled to have their views taken into account but can be overruled by a court or a person with parental responsibility.

Who can make a Living Will? Anyone over the age of 18 can make a Living Will. It is a way of ensuring doctors do not give you certain medical treatments against your wishes.

Why make a Living Will? You can choose in advance the circumstances in which you would want to discontinue medical treatment. You can use a Living Will to specify which organs, if any, you would like to donate after your death.

Who should I tell? Although not obligatory, it is advisable to discuss your intention to make a Living Will with a Healthcare professional in the first

instance. The existence of a Living Will and contact person should be recorded in your medical records. If possible a copy of the document should be kept with the medical records. It is however your responsibility to let all the health professionals treating you know about your Living Will, where it is stored and who you would like them to consult if the time comes for it to be used or revised. You should also share this information with your family.

When is a Living Will used? It is important to remember that a Living Will can only be executed or your nominated person consulted if you are incapacitated and are unable to communicate your views you can alter or cancel your Living Will at any time but it is your responsibility to let your GP and anyone else concerned know that you have done this.

How can I make a Living Will? You can put your requirements in writing or use a specially pre-printed form. You can ask for help from an advocacy organization such as Age Concern or the Alzheimer's Society. This is important since new legislation takes/took effect on 1 October 2007. It is important that your Living is updated at least every 5 years.