This guideline applies to all patients care for by Essex Partnership University NHS Foundation Trust (EPUT). The guideline will ensure that all health and social care professionals are aware of the broad legal (including those arising under the Mental Capacity Act 2005) and the ethical issues related to the use of Advance Decisions and Advance Statements and will ensure that the risks, legal or otherwise, associated with their use are minimised.

The guideline outlines the standards for the care of patients who wish to make or already have an Advance Decision or Advance Statement. It will ensure that practice is evidence based and that there is a systematic and multi-disciplinary approach to the delivery and care of patients across the Trust.

The Trust monitors the implementation of and compliance with this clinical guideline in the following ways;

- Record keeping
- Clinical Supervision and Appraisal
- End of Life Care Competency Framework
- End of Life Care Dashboard
- End of Life Care audit
- Datix reporting
- Patient and Carer Feedback

**SCOPE**

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The Director responsible for monitoring and reviewing this policy is Executive Nurse
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1.0 INTRODUCTION

1.1 Essex Partnership University NHS Foundation Trust – EPUT is committed to complying with statutory and regulatory requirements to promote a culture that assures the safety of our patients, their families, carers, staff and visitors. It is a general principle of law and medical practice that adults have a right to consent to or refuse treatment. The courts have recognised that adults have the right to say in advance what their care wishes are and whether they want to refuse a specified treatment if they lose capacity in the future – even if this results in their death. A valid and applicable Advance Decision to refuse treatment has the same force as a contemporaneous decision. This has been set out in the Mental Capacity Act (2005) which came into force in 2007. The ability to make an Advance Decision to refuse treatment and make statements regarding future care is also supported by NICE Guidance and the End of Life Care Strategy (2008).

This puts the decision on a statutory footing and is applicable when:

1.1.1 A person is 18 years or older.
1.1.2 The person has the capacity to make an Advance Decision about his/her treatment.

1.2 These guidelines provide the operational requirements that underpin the Trust and are directed at all health and social care staff working within the organisation to complete and support Advance Statements and Advance Decisions.

1.3 An Advance Statement is an expression of a person’s wishes, should they become unwell. It can be for any reason relating to their care other than to refuse treatment and is used to support a best interest decision.

1.4 An Advance Statement is not legally binding but expresses choice and preferences that should be respected and acted upon by staff (unless there are particular circumstances that prevent staff from doing so).

1.5 If a valid and applicable Advance Decision exists and the person has now lost capacity, it has the same effect as if the patient has capacity and makes an informed decision to refuse treatment.

1.6 An Advance Decision is a legally binding decision providing it is documented and completed correctly under the Mental Capacity Act 2005 guidance.
1.7 ‘Patient’ will be the terminology used throughout this document and the document will refer to a patient irrespective of the care setting they are in.

2.0 DUTIES

2.1 The Chief Executive is responsible for:
- The principles of this guideline and other associated procedures are implemented across the organisation.
- The availability for any necessary financial resources to ensure staff are trained appropriately.

2.2 The Executive Nurse will ensure:
- To provide leadership and steer at organisational level.
- Clinical Guidelines are embedded into clinical practice and in ensuring these are updated regularly.
- That any clinical risk issues identified are addressed with relevant line managers.
- The implementation of national guidance in relation to Advance Decisions and Advance Statements.
- Clinical and Executive Leadership.

2.3 The Trust’s Medical Director will ensure:
- To provide leadership and steer at organisational level.
- Ensure Clinical Guidelines are updated regularly.
- That any clinical risk issues identified are addressed with relevant line managers.
- The implementation of national guidance in relation to Advance Decisions and Advance Statements.
- Clinical and Executive Leadership.

2.4 The Trust’s Consultant Psychiatrists are responsible for:
- Ensuring that all the medical staff, under their supervision are aware and understand EPUT guidelines.
- Staff receive appropriate and correct training.
- The monitoring the implementation of this guideline via clinical audit and supervision.

2.5 Trust Directors and Senior Management are responsible for:
- Disseminating, implementing and monitoring this guideline within their services via clinical audit and supervision.
- Ensuring that EPUT policies and procedures are followed.

2.6 Managers and other Persons in Charge will ensure:
- The procedures and principles detailed within this guideline are followed, to ensure best practice and that national guidelines are met.
- Staff receive appropriate and correct training.
- The monitoring the implementation of this guideline via clinical audit and supervision.
2.7 Individual Staff-members will ensure:
- that the principles contained within this guideline are implemented;
- adherence to EPUT policies and procedural guidelines;
- Where a member of staff is made aware of the existence of an Advance Decision or Advance Statement, they will inform others in the care of the person (i.e.: Community Teams, Inpatient/ Acute Trusts / Residential and Nursing Home Teams and vice versa).

2.8 Patients and Carers
Have a duty to inform staff of the existence of an Advance Statement or Advance Decision and to ensure staff are in receipt of an up to date copy.

3.0 OVERVIEW AND DEFINITIONS

3.1 The principles of the Mental Capacity Act 2005 are intended to be both enabling and supportive of those who lack capacity. Decision makers should respect the diverse needs and circumstances of each person so that they might protect people who lack capacity to make particular decisions, but also maximise their ability to make decisions, or to participate in decision-making, as far as they are able to do so.

3.2 Advance Decisions and Advance Statements allow patients to make important decisions about their future care and treatment. Providing them with a voice to express choices for future care and advance decisions to refuse treatments.

3.3 An Advance Statement is an expression of a person’s wishes or preferences, made when they have the capacity to do so, detailing their choices for care and what they would like to happen should they become unwell. An Advance Statement is not legally binding but expresses choice and preferences that should be respected and considered by staff when a best interest decision is made.

3.4 An Advance Decision enables someone, aged 18 years and over, while still having mental capacity, to document their wish to refuse specified medical treatment for a time in the future when they may lack the capacity to consent to or refuse that treatment. It is governed by the Mental Capacity Act 2005 and is a legally binding decision.

3.5 Advance Decisions are sometimes referred to as Advance Directives or Living Wills. These terms were used before the Mental Capacity Act 2005 was introduced and, going forward staff should use the term Advance Decision so as to avoid confusion. However, it should be noted that a document entitled Advance Directive or Living Will may constitute a valid Advance Decision and must be considered.
4.0 MENTAL CAPACITY

4.1 To make either an Advance Decision or Advance Statement a patient must have the mental capacity to do so.

4.2 Section 2(1) of the Mental Capacity Act 2005 states that:

“... a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.”

4.3 Therefore a person lacks capacity if:

4.3.1 They have an impairment or disturbance (e.g. a disability, condition or trauma) that affects the way their mind or brain works, and;
4.3.2 The impairment or disturbance means that they are unable to make a specific decision at the time it needs to be made.

4.4 Decisions on mental capacity must be issue specific and it should always be assumed that a person has the mental capacity to make a particular decision unless it is assessed that they do not have that capacity.

4.5 Advance Decisions and Advance Statements only come into force if the person subsequently loses capacity. Until that point they can make their own decisions on specific issues.

5.0 ADVANCE STATEMENTS

5.1 A person must be 18 years old and have the capacity to make an Advance Statement. The Trust Policy on Mental Capacity, which includes Children and Young People from the age of 16 years, provides guidance on those between 16-18 years. A formal capacity assessment should be documented using an Assessment of Capacity Form and a Best Interest Decision Form. Capacity must be assessed on a decision by decision basis.

5.2 An Advance Statement is a statement of beliefs and values which can assist health care professionals in making best interests decisions. An Advance Statement is not legally binding. However, clinicians should take them into account as an important factor when making best interests decision. They do not have to follow them, but should always consider them; best practice would include a multi-professional approach inclusive of the patient/family/carers.

5.3 An Advance Statement is one way to recognise the individual’s expertise in the management of crisis in their own situation. It allows a person to document aspects of their care or treatment that they believe has worked in the past, communicating choices and what is important to them. This allows for their understanding and wishes for staff to deliver a holistic person centred approach to their future care.
5.4 There is no legal requirement for the format of an Advance Statement but they may include:

5.4.1 Any aspect of care that is important to the patient and may help carers to be fully involved in their care.
5.4.2 Signs and symptoms which may show when they are becoming unwell and preferred crisis interventions, so that the attention of the treating clinician is drawn to concerns of the patient’s preferences, which can help with treating them swiftly.
5.4.3 Treatments which have helped in the past and why, along with those that have not helped.
5.4.4 Domestic and financial arrangements, e.g. food, beliefs and preferences for pets and children, religious beliefs, which may help staff and other friends and relatives in a crisis.
5.4.5 Where their preferred place of care and death would be.

5.5 Refer to the Mental Health Code of Practice, Chapter 9 if you require further clarity and NICE guidelines - making decisions about your care.

6.0 ADVANCE DECISION TO REFUSE TREATMENT

6.1 A person must be at least 18 years old and have capacity to make an Advance Decision to refuse treatment.

6.2 An Advance Decision to refuse treatment is legally binding if it is valid and applicable. Staff must check that this is the case. If it is, it has the same effect as if the patient had capacity to tell us now and make a decision to refuse a specific treatment.

6.3 To be valid and applicable an Advance Decision to Refuse Treatment must be:

6.3.1 Clear - it can be in layman’s terms but cannot be vague. It needs to be Signed, dated, witnessed and it must state clearly that the decision applies. The patient must sign that even if their life is at risk as a result of the decision it must apply.
6.3.2 Situation specific - it must be relevant to specific medical circumstances or treatments.
6.3.3 It must have been made voluntary by the patient and not made under pressure from anyone else.
6.3.4 Must be made when the patient has capacity.
6.3.5 Consistent with subsequent behaviour - e.g. it must be the current Advance Decision in force and not replaced by another Advance Decision or Lasting Power of Attorney.

6.4 Unless the Advance Decision is to refuse life sustaining treatment there is no requirement that it be put in writing by the patient. Therefore a verbal advance decision may be legally binding; staff must be very clear in how they record such conversations or verbal wishes within patient records.
6.5 If an individual wants to make an Advance Decision to refuse life sustaining treatment there are additional requirements as follows:

6.5.1 The Advance Decision must be in writing.
6.5.2 It must state clearly that the decision applies even if life is at risk.
6.5.3 It must be signed and witnessed. Discussed and witnessed by a health/social care professional who is familiar with the patient’s condition and wishes and has provided them an informed choice the implications of their decision.

6.6 If an Advance Decision is not applicable or valid it must still be considered as part of any best interest decision.

6.7 An Advance Decision cannot:
6.7.1 Refuse basic nursing care aimed to sustain comfort.
6.7.2 Refuse food and drink (NB but can refuse artificial nutrition and hydration).
6.7.3 Refuse basic medication to maintain comfort.
6.7.4 Demand inappropriate treatment.
6.7.5 Refuse treatment for a mental disorder whilst detained under the Mental Health Act 1983.
6.7.6 Require anything unlawful, for instance assisting suicide or euthanasia.

If staff finds that such a request is being made by the patient either in writing or verbally, they should discuss this with their line manager, and document the discussion in writing in the patient record, informing the patient they have a requirement to escalate the discussion.

Further information about Advance Care Planning discussions and planning for your future can be found at:

Appendix 1 – Guidance Sheet. Information for patients and carers and planning our future care can be found at:

http://www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare

7.0 ADVANCE DECISIONS AND LASTING POWERS OF ATTORNEY (LPA)

7.1 The donee of an LPA (i.e. the attorney appointed by the person making an LPA) can make decisions on behalf of the donor (patient) when they lack capacity, as long as the decision to be made falls within the area of authority (decision making power) that is offered in the LPA.

7.2 However the donee cannot make a new Advance Decision on behalf of the donor.
7.3 An existing Advance Decision will become invalid if it covers the same area of treatment that the donee (of an LPA subsequently made) can decide upon while the donor is lacking capacity. However, all Advance Decisions should be considered in the best interest of the donor by the donee.

7.4 If the treatment in question is "life-sustaining" then the donee of an LPA can only make decisions if the conditions in the LPA specifically mention authority to decide about "life-sustaining" treatment.

7.5 It would be important to note the time sequence as to when a particular Advance Decision and LPA were made. If an Advance Decision was made after an LPA then it will stand. If an Advance Decision was made before an LPA then it is up to the donee of the LPA to decide whether or not to honour the wishes contained within the Advance Decision that the donor of the LPA had made. A donee of an LPA has the obligation to work in the donor's best interests at all times, but should give consideration to any Advance Decisions previously made.

8.0 ADVANCE DECISIONS AND ADVANCE STATEMENTS AND THE MENTAL HEALTH ACT 1983

8.1 Advance Decisions and Advance Statements may be overridden when an individual is detained under the Mental Health Act 1983 (MHA). (Chapter 9, MHA Code of Practice).

8.2 For patients who are detained under the MHA (sections 2, 3, 37, 47 or 48) and the proposed treatment is for their mental illness, Advance Decisions and Advance Statements which refuse medical treatment do not apply.

8.3 For those on Community Treatment Order, Advance Decisions must be followed unless the individual is recalled to hospital by their Responsible Clinician. (Chapter 4, MHA Code of Practice).

8.4 For individuals under MHA provisions which convey no treatments powers (sections 4, 5(2), 5(4), 35, 135(1) and 136, guardianship and conditional discharge), Advance Decisions to Refuse Treatment will continue to have authority.

8.5 Where the proposed treatment does not relate to mental illness Advance Decisions and Advance Statements must be considered as they must continue to apply.

8.6 Even when they are not binding, views expressed in Advance Decisions and Advance Statements should be taken into account when making decisions about treatment to be given under the powers of the Mental Health Act. These should act to support best interest decisions at all times.
9.0 IF A PATIENT WISHES TO MAKE AN ADVANCE DECISION

9.1 To make an Advance Decision it is not necessary to involve a solicitor. However, the law relating to Advance Decisions is detailed and the consequences of any misunderstanding might be unfortunate. To make the Advance Decision the person may consider taking legal advice and staff should encourage the patient to do so.

9.2 It is recommended (although not compulsory) that people discuss the decision to make an Advance Decision with their GP or other appropriate health or social care professionals.

9.3 Staff members should not witness or counter-sign an Advance Decision without having an understanding of the patient’s condition and be involved in having a professional relationship with the patient’s care. It must only be counter-signed by a registered health or social care professional and this should be recorded in the patient’s records. All discussions and who was involved in the discussions must be documented in the patient records and discussed with the line manager.

9.4 Appendix 2 outlines an example of how an Advance Decision could be drafted. There is a national form and local advance care plans used by partner organisations which include Advance Decision to refuse treatment documents. Staff must be aware that there are local variations.

9.5 Staff must ensure they are confident that the form that is being used is relevant and covers all the legal needs for recording in accordance with the National guidance. They should ensure that patient records are updated and the GP is informed of any Advance Decision to Refuse Treatment.

10.0 IF A PATIENT WISHES TO MAKE AN ADVANCE STATEMENT

10.1 The care co-ordinator or lead professional should encourage a patient to write an Advance Statement when they have capacity to do so and their mental health is considered stable. They may use the form attached in Appendix 3 to do so or draft their own form - there are a number of other forms available through local variations. Staff must ensure that the form is updated and relevant, empowering patients to ensure they update these appropriately at least six-twelve monthly.

10.2 The care co-ordinator or lead professional may help the person to write an Advance Statement, or allocate another worker within the team. Alternatively, the person can contact Age Concern, Rethink or Mind, or alternative Mental Health or voluntary agencies to support them to complete one. In either case the patient must provide their care co-ordinator with a copy of the Advance Statement to be recorded in the patient’s records and their GP should be informed.

10.3 Appendix 3 outlines and example of how an Advance Statement could be drafted.
11.0 WITHDRAWING AN ADVANCE DECISION OR ADVANCE STATEMENT

11.1 A patient may amend or withdraw their Advance Statement or Advance Decision at any time while they retain the capacity to do so.

11.2 A withdrawal needs not be in writing, see Appendix 2 and 4.

11.3 It is important that the Advance Statement or Advance Decision is updated every six months or at least yearly to ensure misinterpretation of it being withdrawn. Staff must ensure they ask the patient and update the medical notes to reflect it is updated.

12.0 USE OF ADVANCE DECISIONS AND ADVANCE STATEMENTS BY STAFF WORKING WITHIN EPUT

New patients

12.1 Promptly on admission to a service, staff members need to establish if an Advance Decision and/or an Advance Statement is in place. They should ask the patient and their relatives and request a copy.

12.2 The patient and the person who supports the Advance Decision being made must take responsibility to ensure this is recorded in the GP records and other relevant medical records for clarification. They must be empowered to ensure they share confidently their Advance Decision to Refuse Treatment with the services they attend and ensure family/nominated person is aware. This will support them through services that are new to them.

12.3 It would be expected that the patient and their carers/relatives/nominated person would also take responsibility of ensuring that all new providers are made aware of any existing Advance Decisions or Advance Statements the patient has made. EPUT staff must also make this communication to avoid any future unintended non-compliance with an Advance Decision or Advance Statement.

13.0 RECORD KEEPING

13.1 Whenever an Advance Decision or Advance Statement is made the document or notification form (Appendix 3 – Advance Statement Booklet) must be scanned into the patient’s electronic records by the care co-ordinator or lead professional that has assisted with the completion. The GP should also be informed that the decision has been made. The document should be patient held and the patient/carer must be supported to understand their responsibility in storing and sharing this document with other services throughout their illness.
Verbal Advance Decisions

13.2 Verbal instructions can amount to a valid decision, unless it is a decision to refuse life-sustaining treatment (this must be in writing). However, in order to avoid any uncertainty over the validity, and to ensure that it is carried out exactly as the maker would wish, it is recommend that it should be put in writing and witnessed.

13.3 The interpretation of an Advance Statement would be left to the understanding of the Healthcare professionals. Therefore where ever possible it must be in writing to prevent the wrong interpretation of whether it is valid and applicable.

13.4 Healthcare professionals must document a verbal Advance Decision to Refuse Treatment in a person’s healthcare record. This will produce a written record that could prevent confusion about the decision in the future. The record should include:

13.4.1 A record that the decision was discussed, content of the decision and state that it was the person’s understanding and own decision. It must apply if the person lacks capacity to make treatment decisions in the future.

13.4.2 A note of the decision, the treatment to be refused and the circumstances in which the decision will apply must also be recorded.

13.4.3 Details of someone who was present when the verbal Advance Decision was recorded and the role in which they were present (for example, healthcare professional or family member), and

13.4.4 Whether they heard the decision, took part in it or are just aware that it exists.

Withdrawal

13.5 If a patient indicates they want to withdraw or amend their Advance Decision or statement, this should be recorded in the notes in the relevant section. The patient should be encouraged to use the Withdrawal of Advance Decision/Advance Statement document Appendix 4. Staff members must ensure they update records and inform the GP of any changes.

14.0 STAFF’S REQUIREMENT TO ACT ON AN ADVANCE DECISION

14.1 It is the responsibility of the healthcare professional that is in charge of the person’s care when the treatment is required to decide whether there is an Advance Decision which is valid and applicable to the circumstances. It would be best practice for a Multi-disciplinary team - MDT discussion.
14.2 Before acting on an Advance Decision staff must be satisfied that the Advance Decision is valid and applicable (see section 4). In particular, staff must be sure to check that:

14.2.1 The patient’s capacity at the time of making the Advance Decision was not affected by illness, medication, false information or pressure from other people.
14.2.2 At the time of making the Advance Decision the patient had made an informed choice by receiving sufficient relevant information about the implications of any refusal of treatment including any increased risk of death.
14.2.3 There are no reasonable grounds for believing that there has been a change in circumstances which, if the patient had known about the change, would have affected the making of the decision.
14.2.4 The Advance Decision has not been withdrawn or amended when the patient had capacity to do so.
14.2.5 The patient has not done something that is clearly inconsistent with the Advance Decision.

14.3 Staff should also consider:

14.3.1 The length of time that has passed since the Advance Decision.
14.3.2 Whether there have been any relevant developments in medical treatment that the patient did not foresee.
14.3.3 Whether there have been any significant changes to the patient circumstances which might affect the validity of the Advance Decision.

14.4 If an Advance Decision is considered valid and applicable it must be followed. As long as the patient had capacity at the time of making the Advance Decision the reasons for refusal are irrelevant.

14.5 Any decision that an Advance Decision is no longer deemed to be valid and applicable, should:

14.5.1 Only be made after very careful consideration and with the input of the MDT, including the GP and family.
14.5.2 It must be very clearly and carefully evidenced in the notes; and
14.5.3 Must not be a routine course of action.

14.6 To deliberately ignore an Advance Decision may be a criminal offence for which the member of staff is held liable.

14.7 Health and Social Care professionals will be protected from liability if they treat a person because, having taken all practical and appropriate steps to find out if the person has made an Advance Decision to Refuse Treatment, they are not satisfied that a valid and applicable Advance Decision exists.

14.8 If there is a dispute about whether there is a genuine Advance Decision, this may go to be resolved by the Court of Protection. Healthcare Professionals can treat whilst the court makes a decision.
14.9 Some Health or Social Care Professionals may disagree in principle with an individual’s decision to refuse life-sustaining treatment. They do not have to act against their beliefs; however, they must not abandon patients or act in a way that affects their care. Such matters would be dealt with under the disciplinary procedures.

14.10 If, following an MDT discussion including the GP, it is felt that an Advance Decision is not valid or applicable, then this must be properly justified, documented within the clinical records by the chair of the MDT or their nominated deputy, or GP. This should be relayed to the patient immediately, who should then be offered access to Advocacy. As well as a verbal explanation it should also be put in writing and given to the patient as soon as they regain capacity.

14.11 If the patient is not given this information or they are dissatisfied by the explanation given, they may require support to resolve this. They can do this through the Patient Experience Team (0800 085 7935). If the patient remains dissatisfied they can make a formal complaint to the Complaints Department on 01268 407817.

15.0 STAFF’S REQUIREMENT TO ACT ON AN ADVANCE STATEMENT

15.1 If the Advance Statement is clear, unambiguous, signed and dated and detailed appropriately it should be taken into account when a decision is being made about that individual.

15.2 Statements that express preferences or requests should be followed where possible but the clinical team’s final decision should always be based on the person’s best interests as assessed in the current circumstances.

15.3 If, following an MDT discussion which can include the GP the patient’s wishes or preferences contained within their Advance Statement cannot reasonably be met then this must be properly justified and documented within the clinical records by the chair of the MDT or their nominated deputy. This should be relayed immediately to the patient who should be offered access to Advocacy. As well as a verbal explanation it must be put in writing and given to the patient as soon as they regain capacity.

15.4 If the patient is not given this information or they are dissatisfied by the explanation given, they may require support to resolve this. They can do this through the Patient Experience Team (0800 085 7935). If the patient remains dissatisfied they can make a formal complaint to the Complaints Department on 01268 407817.

15.5 The patient may choose to carry a contact card with him/her to indicate that they do have an Advance Decision or Advance Statement in place. See Appendix 5A & 5B.
16.0 MONITORING OF IMPLEMENTATION AND COMPLIANCE

16.1 This Clinical Guideline will be disseminated throughout the organisation via the Trust intranet.

16.2 Team Managers will be required to provide assurance statements to their Associate Locality Director that this clinical guideline has been discussed at their Team Meeting and rolled out within teams.

16.3 Implementation and compliance with this clinical guideline will be audited as part of the Trust Annual Clinical Priority Audit programme as part of the record keeping Audit.

16.4 Records of Advance planning is reported on as part of the End of Life Care dashboard within EPUT. Monitoring the trends will support compliance of these guidelines.

17.0 REFERENCES

National Guidance
- Code of Practice, Mental Health Act 2015
- Mental Capacity Act 2005
- Mental Health Act 1983
- Code of Practice, Mental Capacity Act 2005


Other Policies / Clinical Guidelines

The following policies/guidance must be read and used in conjunction with this clinical guideline:

- Adverse Incident & Serious Untoward Incident Reporting Policy
- Risk Assessment Policy
- Care Programme Approach Policy
- Supervision Policy
- Consent to Treatment Policy
- Mental Capacity Act Policies
- Mental Health Act Policies
- ECT policy
- CPR policy
- Complaints Policy
- Safeguarding Adults Policy