

Advance Decisions and Statements for Mental Health

including the decision to refuse treatment

Patient information leaflet



What is an Advance Decision?

An advance decision is something you make if you want to refuse specific treatment should you become unwell. It is made when you are well and are able to understand the implications of refusing the specific treatment. An advance decision will always be in the negative (refusal), you should clearly specify the treatment that you are refusing, why you are refusing it and in what circumstances.

Who can make an Advance Decision?

Anyone over the age of 18 who has the capacity to decide how they don't want to be treated if they become unwell.

What is an Advance Statement?

An advance statement is something that you complete when you are well regarding your care and treatment should you become unwell. During a crisis you may be too ill to make an informed decision. This is a way of telling people what you want to happen, before that situation occurs.

Who can make an Advance Statement?

Anyone over the age of 16 who has the capacity to make decisions and would like to decide how their care will be managed if they become unwell.

Why should I make an Advance Decision or Advance Statement?

During a crisis you may be too ill to make informed decisions or express what you want or arrangements that you need to be made. This is a way of telling people what you do or don't want to happen, before that situation occurs.

Advance Decisions

What type of things could be in an Advance Decision?

Your advance decision should specify the treatment you are refusing. If this is medication you should name the drug(s) you don't want. It should give the reasons behind your decision, for example if it is because of specific side effects and the circumstances in which this refusal applies. If your refusal relates to life sustaining treatment then you need to include in a document that the decision to refuse treatment applies even if your life is at risk.

Is an Advance Decision legally binding?

An advance decision is binding on healthcare professionals providing it is both valid and applicable. It must be clear that when you made the decision you were properly informed about the implications and had capacity to make the decision. This is why it is important to give the reasons for not wanting specific treatments.

An advance decision does not need to be written down but it is easier to establish what you are refusing and in what circumstances you want to refuse it if it is written down. However, if your refusal is for life sustaining treatment then it must be written, witnessed and signed.

An advance decision can be over-riden by the Mental Health Act 1983 but only as regards treatment for your mental illness and professionals must still have regard to it.

Mental Health Act 1983 - Use of ECT

ECT is subject to special safeguards of Section 58A of the Mental Health Act 1983. This includes when a patient has given consent, or is incapable of consent and is detained under the Mental Health Act 1983. A valid and applicable advance decision covering use of ECT can not be overridden. However ECT can still be used in emergencies where it is necessary to save life or prevent serious deterioration.

How do I make an Advance Decision?

An advance decision can be made verbally but it is clearer if it is written down. You can write it yourself, or you can write with help from your Care Co-ordinator/Lead Professional or another person you ask to assist you. This may be a carer, family member, friend or partner, a health professional or a solicitor. You may write it during a meeting with your care team or in a care coordination review, or at any other time.

Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust has a special form for an advance decision that makes it easy but you can use any format you want to.

Who should I discuss the content of my Advance Decision with?

If you are thinking about making an advance decision it is recommended that you get advice from the health care professional most closely involved with your current treatment or an organisation that can provide advice in relation to your specific condition or situation. This will help you to have all the information you need to make an informed decision.

You may want to get legal advice to make sure you express your decision clearly and accurately.

What happens to the document when it is completed?

When you have written your advance decision, give it to your Care Co-ordinator/Lead Professional. They will ensure that, with your agreement, all members of your care team e.g. Consultant, Community Psychiatric Nurse, Social Worker, GP etc. have a copy and will look at it when they need to.

Advance Statements

How do I make an Advance Statement?

An advance statement is the document that you write yourself, or you write with help from your Care Co-ordinator/Lead Professional or with help from another person you ask to assist you. You may write it during your care co-ordination review, or at any other time you wish. Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust has a special form that you may use which makes it easy to do but you can use any format you wish.

What type of things could be in an Advance Statement?

The advance statement will set out your wishes about what you would like to happen if you become unwell.

The statement can include issues such as:

- Who people should contact if you become unwell.
- Your wishes regarding preferred medication.
- What treatment has worked well for you in the past and what has not been so helpful.
- Any special needs that you may have with regard to diet, health, religion, disability, etc.
- Arrangements that you wish to be made for your children/dependants or family pets.
- How you would like to make your home secure, and who should be responsible for this.

What happens to the document when it is completed?

When you have written your advance statement, give it to your Care Co-ordinator/Lead Professional. They will ensure that, with your agreement, all members of your care team e.g. Consultant, Community Psychiatric Nurse, Social Worker, GP etc. have a copy and will look at it when they need to.

It is also a good idea to give copies of the document, or at least of the appropriate sections of it, to any of the people that you have named as being responsible for caring for dependants, pets, or who you have asked to look after the security of your home.

Is the document legally binding?

An advance statement sets out your wishes and professionals will always take these into account but it is not legally binding. There are certain circumstances where they may have to override your wishes; for example, if there is any risk to a child or yourself.

Could someone other than my Care Co-ordinator/ Lead Professional help me to complete the Advance Statement?

Anyone that you choose may help you to complete the advance statement. However, it is important to note that decisions regarding your care and treatment should reflect what is actually achievable and possible. You may wish to write the advance statement with a friend, colleague or user organisation, and then discuss this with your Care Co-ordinator/Lead Professional.

Do I need to discuss the content of my Advance Statement document with family and friends?

If you have identified a member of your family or friend as being responsible for child care, care of pets, home security, etc., it is advisable that you discuss this with them prior to seeking their agreement. If you don't it may mean it is difficult for your wishes to be followed.

Can I insist on certain medication and treatments?

You cannot insist on receiving certain medication or treatments, but you may express an opinion about treatments such as identifying which medication has worked for you in the past.

If I require in-patient treatment can I insist on being admitted to a particular ward, or access to a particular service?

You cannot insist on an individual ward, department or hospital, but you can express a preference.

Can I change/withdraw my Advance Decision or Advance Statement?

Yes you can change either document at any time, but please ensure that the professionals involved in your care and anyone else who has a copy of the document have a copy of the most up to date version. There is a form to help you inform people.

If you have an advance statement it should be reviewed as part of your care review meeting or Care Co-ordination review.

Where can I get a copy of an Advance Decision or Advance Statement form?

You can obtain a copy from your Care Co-ordinator/Lead Professional or advocacy service.

People who can support you

An advocate

An advocate is someone who acts on your behalf to support you in making decisions whilst you are an informal/voluntary patient.

You may be able to have an advocate, please ask a member of staff for details of the advocacy services available.

Patient Advice and Liaison Service (PALS)

The Patient Advice and Liaison Service is a confidential NHS service which acts independently to provide information and advice about all NHS services and help sort out any problems you may have quickly.

There are PALS officers in most areas of the Trust. PALS officers can be contacted in the following ways:

- **South of Tyne:** 0800 328 4397
- **North of Tyne:** 0800 032 0202

You can also write to PALS at:

- **For South of Tyne Areas**
Patient Advice and Liaison Service
Garden Lodge, Hopewood Park
Waterworks Road,
Ryhope
Sunderland
SR2 0NB
- **For North of Tyne Areas**
North of Tyne PALS
FREEPOST PALS
The Old Stables
Grey's Yard
Morpeth
NE61 1QD

Or ask a member of staff to contact the PALS officer on your behalf.

What if I have a comment, suggestion, compliment or complaint about the service?

If you want to make a comment, suggestion, compliment or complaint you can:

- talk to the people directly involved in your care
- ask a member of staff for a feedback form, or complete a form on the Trust website www.cntw.nhs.uk (click on the 'Contact Us' tab)
- telephone the Complaints Department Tel: 0191 245 6672
- email complaints@cntw.nhs.uk Please note that information sent to the Trust via email is sent at your own risk

We are always looking at ways to improve services. Your feedback allows us to monitor the quality of our services and act Upon issues that you bring to our attention.

You can provide feedback in the following ways:

- the quickest way for you to do this is to complete our short online survey at www.cntw.nhs.uk/poy
- complete a Points of You survey, available on wards, reception areas or from staff.

Further information

- Deciding Right – An integrated approach to making care decisions in advance with children, young people and adults, V11, NHS North East, September 2011
- Additional information and forms regarding advance decisions and advance statements in relation to end of life care can also be found on the Trust intranet.

References

- CNTW(C)34pgn -MCA-PGN-02 - Advance Decision to Refuse Treatment and Advance Statements

Glossary

Word or phrase	Meaning
Advocacy Service	Someone who acts on your behalf to support you in making decisions.
Care Co-ordination Review	Meeting used to help and support people with mental health problems.
Care Co-ordinator	If you have complex needs, this is the person who will be your main contact and who will ensure you receive the care you need.
Carer	This could be a family member, friend or advocate who provides care and support for you.
Consent	Where you have given your agreement.
CPN	Community Psychiatric Nurse.
GP – General Practitioner	Your doctor that you would usually see if you were physically unwell.
Lead Professional	If you have low level needs, this is the person who will be your main contact and who will ensure you receive the care you need.
Social Worker	This professional would assess your social care needs and provide support to help meet them.

Further information about the content, reference sources or production of this leaflet can be obtained from the Patient Information Centre. If you would like to tell us what you think about this leaflet please get in touch.

This information can be made available in a range of formats on request (eg Braille, audio, larger print, easy read, BSL or other languages). Please contact the Patient Information Centre
Tel: 0191 246 7288

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