

Planning your future care

Advance statements and advance decisions

This factsheet may be helpful if you are worried that you won't be able to make decisions for yourself in future. It looks at what an advance statement and an advance decision is, how to make them and what happens if they aren't followed by professionals.

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- An advance statement and advance decision are documents to say how you would like to be treated in the future if you can't decide for yourself.
 - You can only make an advanced statement or advance decision if you have mental capacity.
 - An advanced decision is a document to state which treatments you want to refuse in the future.
 - An advanced decision is sometimes known as an 'advance directive' or a 'living will'.
 - An advance decision is legally binding.
 - You can use an advance statement to say who you would like to manage your affairs, such as paying bills or looking after children.
 - Doctors should follow your advance statement. Though there is no legal obligation too.

This factsheet covers:

1. [What is an advance statement and advance decision?](#)
2. [What is the difference between an advance statement and advance decision?](#)
3. [Can I make an advance statement or advance decision if I am unwell?](#)
4. [What happens to my advance statement or advance decision if I am detained under the Mental Health Act?](#)
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1. What is an advance statement and advance decision?

You may lose the ability to make a decision for yourself in the future because of illness or injury. This is known as losing mental capacity.

An advance statement or advance decision will explain to professionals and loved ones what you would like to happen with your care and treatment in the future.

You may want to make an advance statement or advance decision to feel in control of what happens to you if you become unwell. Or to help your loved ones to care for you.

You don't have to make an advance statement or advance decision if you don't want to.

What happens if I don't have an advance statement or advance decision?

Your healthcare professionals will make welfare decisions in your best interests when the decisions need to be made.¹ This will only happen if you lack mental capacity to make the decision yourself.²

Another option is to make a Lasting Power of Attorney (LPA). An LPA is a legal document that allows someone that you trust to make welfare decisions on your behalf.³ An LPA will only ever be able to make welfare decisions on your behalf if you lack mental capacity.⁴ But you need to have mental capacity to make the LPA.⁵

What happens if I have an LPA but I also want to make an advance decision?

Your LPA will not be able to override your advance decision if it is valid and applicable.⁶

You can find more information about, '**Mental capacity and mental illness**' at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

2. What is the difference between an advance statement and an advance decision?

Advance statement

An advance statement is a general preference about your treatment and care.⁷

It isn't legally binding, but medical professionals should still make a practical effort to follow your wishes. The Mental Capacity Act states that decisions about your care and treatment should be made in your 'best interests'. Your advance statement can reflect your views, beliefs and

values. This information will be useful when people make decisions that affect you. An advance statement is also known as a 'statement of wishes.'

Advance decisions

An advance decision is legally binding. It gives you the legal right to refuse specific medical treatment in future when you may not have the mental capacity to make the decision for yourself at that time. An advanced decision can't be used for anything else.⁸ For example if it has information about what treatment you want, health professionals don't have to follow it. This information will be treated the same as an advance statement.

Your decision must be clear to be legally binding.⁹ Legally binding means it is against the law if health professionals don't follow it.

You have to be 18 or older and have mental capacity to make an advance decision.¹⁰

An advance decision is also known as an 'advance directive' or a 'living will.'

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3. Can I make an advance statement or advance decision if I am unwell?

You can make an advance statement or advance decision if you are unwell. But you need to have mental capacity. Doctors and other professionals don't have to follow your instructions if you didn't have mental capacity at the time you made it.

What does mental capacity mean?

If you have mental capacity you can:¹¹

- understand information that is relevant to the decision,
- remember the information,
- be able to weigh up the information to help you to make your decision, and
- communicate your decision.

Weighing up information is about thinking about the good points and bad points of a decision. And showing that you understand any risks.

You can communicate your decision in different ways. Such as using diagrams or pictures, gestures or talking.¹²

Your mental capacity can fluctuate. This means that sometimes you may not have capacity to make a certain decision but other times you will have capacity.

You will always be thought to have mental capacity unless it can be proven that you don't.¹³

You can find more information about ‘**Mental Capacity and Mental Illness**’ at www.rethink.org. Or call our General Enquiries team 0121 522 7007 and ask them to send you a copy of our factsheet.

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4. What happens to my advance statement or advance directive if I am detained under the Mental Health Act?

Advance statement

Being under the Mental Health Act should not affect the way that professionals use your advance statement.¹⁴

Advance decision

Health professionals don’t legally have to follow an advance decision if you are in hospital under the Mental Health Act. But professionals should try to follow what you have written in your advance decision. If they have to use the treatment that you don’t want, they should be able to explain to you why they have had to do it.¹⁵

But there is an exception. If you have an advance decision refusing electroconvulsive therapy (ECT), or your Lasting Power of Attorney (LPA) refuses ECT on your behalf, they can’t give you ECT.¹⁶

But a doctor can ignore your LPA or advance decision if you need ECT to:¹⁷

- save your life, or
- stop you getting very unwell from something that can’t be reversed.

Advance decisions to refuse treatment for physical illnesses or conditions are not affected by you being detained in hospital under the Mental Health Act.¹⁸

You can find more information about:

- Electroconvulsive Therapy
- Mental Health Act

at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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5. How do I make an advance statement or advance decision?

You can tell someone your advance statement or advance decision. Or you can write it down. But if you want to make an advanced decision to refuse life-threatening treatment you will need to write it down.¹⁹ See ‘[How do I make an advance decision to refuse life-sustaining treatment](#)’ for more information.

You could tell a family member, friend or other professional such as your GP. A GP is likely to make a note of the conversation in your medical notes.

We recommend that you write your advance statement or advance decision down so that there is less question about your wishes in the future. It can still be helpful to speak to loved ones about what you have written in your advance statement or advance decision.

What do I put in my advance statement?

There is no set template that you need to use for an advance statement.

The types of things that you could include in your advance statement could be the following.²⁰

- Your treatment preference.
- Where you would like to be cared for. Such as your home, hospital or hospice.
- How you would like a religious or spiritual belief to be reflected in your care.
- How you like to do things. Such as if you prefer a bath or a shower.
- Things that you like. Such as a particular scent. Or if you prefer to be outside or inside. Or your favourite foods.
- Who you would like to look after your children or pets.
- Who you would like to deal with your benefits and bills.
- What happens when you become unwell.

Remember that your advance statement is not a legal document. If there is someone who you would like to look after your benefits and bills or make decisions about your care and treatment you should think about making a Lasting Power of Attorney.

Certain care or treatment that you would like may not be available in future. You can update your advance statement with any changes at any time.

Example of an advance statement:

Name: Jane Smith
Date of Birth: 01/04/1970
Address: 37 Cambridge Road DY7 8TP

I Jane Smith have been detained under the Mental Health Act 3 times to date. Whenever I am detained I tell mental health professionals not to tell my son and daughter information about my medication and care.

But I want my son and daughter to know what medication I am taking and what care I am being given. I also want them to be involved with planning my care on discharge. Even though I will tell professionals that I don't want this to happen. When I become unwell I believe that my son, daughter and other loves ones are plotting against me. Don't tell me that you have told them my information. It will cause me distress.

Don't give me medication through injection. I have always been scared of injections and this adds to my distress. If I will not accept oral medication on its own, put it into my food. I have a good appetite even when I am unwell. This will help me to build trust with staff and hopefully help me to get better quicker.

I also have an advance decision to refuse electroconvulsive therapy (ECT).

I have told my son and daughter that I have made an advance statement and advance decision and given them each a copy. I have also made my GP aware and given them a copy. I have added their contact details below.

GP: Doctor Foster
Address: Roper Way Surgery, DY7 4BJ
Contact number: 0121 478 1365

Daughter: Sharon Smith
Date of birth: 05/06/1990
Address: 37 Cambridge Road, DY7 8TP
Contact number: 07984731244

Son: Peter Smith
Date of birth: 25/02/1993
Address: 52 Birdcage way, CM4 3LY
Contact number: 07845123457

Signed: Jane Smith

Printed name: Jane Smith
Today's date: 15th February 2017

What do I put in my advance decision?

There isn't a set template to follow. But the Mental Health Act Code of Practice suggests that you include the following information.²¹

- Your full name.
- Your date of birth.
- Your home address.
- Any distinguishing features you have such as a birth mark or tattoo. This can be helpful if healthcare professionals need to identify you if you are unconscious.
- The name and address of your GP.
- Whether or not your GP has a copy of your document.
- A statement that the document should be used if you ever lack capacity to make treatment decisions.
- A clear statement of your decision:
 - the treatment to be refused, and
 - the circumstances in which the decision will apply.
- The date the document was written or reviewed.
- Your signature.
- The date of signing.
- A signature from a witness.

There are specific rules that need to be followed if you would like to make an advance decision which refuses life sustaining treatment.

How do I make an advance decision to refuse life-sustaining treatment?

An advance decision to refuse treatment must state exactly what treatment you want to refuse. A general statement is not enough. Include as much information as you can.²²

An advance decision to refuse life sustaining treatment must meet certain criteria:²³

- they must be put in writing,
- you must sign the advance decision,
- you must sign it with a witness with you,
- the witness must sign the document when you are with them, and
- you must include a clear, specific written statement to state that the advance decision will apply to specific treatment even if your life is at risk.

You should discuss an advance decision to refuse life-sustaining treatment with your doctor. They will be able to explain:²⁴

- what kind of treatment may be life-sustaining,
- in what circumstances they will apply, and
- what could happen if you refuse the treatment.

You don't need to get legal advice when you create an advance decision. But you can talk to a solicitor if you would like to. This is likely to cost you money.

Where do I keep my advance statement or advance decision?

Professionals need to know that you have an advance statement or advance decision. If they don't know it exists they can't use it.

You could tell people where to find your advance statement or decision. You could also give them their own copy or get your medical records updated. You could:²⁵

- tell your GP,
- tell your mental health team,
- update your NHS summary care records scheme (SRC),
- tell a friend or relative,
- wear a health alert bracelet,
- carry a crisis card, or
- update a health app on your phone.

What is the summary care records scheme (SCR)?

The SCR is an electronic record of important information about you. It is created from your GP medical records. It can be seen by certain

staff in other areas of the health and care system to help with your care.

You will have a SCR already unless you have told the NHS you do not want one. As a minimum, it includes the following information about you:²⁶

- current medication,
- allergies and details of any previous bad reactions to medicines, and
- your name, address, date of birth and NHS number.

You can ask your GP to include information about your advance statement or advance decision on your SRC.

What is a crisis card or health alert bracelet?

You can carry a crisis card or wear a health alert bracelet which says you have an advance statement or advance decision. A health alert bracelet can be known as medical jewellery. It can help make sure that health professionals know you have one if you can't tell them. They contain information about anything that you would like people to know such as who to contact if you are ill, your doctor's details, diagnosis and your medication.

How do I update my advance statement or advance decision?

You should regularly review and update your advance statement and decision in writing, even if you don't want to make any changes.

You can change your advance decision at any time, as long as you have capacity to do so.²⁷

Professionals only have to follow your advance decision if it is valid and applicable. A recent advance decision is more likely to be valid and applicable to you and your circumstances. This is because your views and circumstances may change over time. Decisions that you made a long time ago aren't automatically invalid or inapplicable but it may raise doubts with professionals.²⁸

A good time to review your advance statement or decision could be at the following times.²⁹

- A new stage in your illness.
- The development of new treatments.
- A big change in your life.

If you change your mind about what it says, you could add information and attach it to your original statement. If you are making a lot of changes you could write a new statement or decision. You should destroy the original advance statement or decision and any copies so health professionals don't get them mixed up.

How do I end my advance statement or advance decision?

You can cancel your advance statement or advance decision at any time as long as you have mental capacity to do so.³⁰ You can cancel in writing or verbally. There isn't a formal process to follow. But you should tell anybody who knew about your advance statement or decision that you have decided to cancel it.

You should destroy the original advance statement or decision and any copies. Or clearly mark that you have changed your mind and they are no longer valid.

You can find more information about '**Legal Advice**' at www.rethink.org. Or call our General Enquiries team 0121 522 7007 and ask them to send you a copy of our factsheet.

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6. What happens if professionals don't follow my advance statement or advance decision?

Advance statement

As part of your advance statement you may ask for something to happen in future such as request a certain type of treatment. But these requests are not legally binding. This means professionals don't have to follow them. Professionals may not go along with your wishes in the following examples.

- A health professional feels that the treatment you asked for is not in the best option for you.
- The treatment you ask for is illegal, such as asking a doctor to end your life.
- Health professionals act in an emergency and there is not enough time to get your advance statement.
- The treatment you want is not available in your area.
- Health professionals believe that you did not have the mental capacity to make the statement.

If health professionals do not follow your advance statement, ask them to explain why. If you are not happy with the explanation, you could make a complaint.

A complaint may help you get answers about why the advance statement was ignored.

Advance decision

If professionals don't follow your advanced decision they could be charged for committing a crime. Or you could sue them in the civil courts.³¹

A valid advance decision refusing treatment is the same as someone with mental capacity refusing treatment. You have the right to refuse treatment when you have mental capacity.

You could make a complaint or get legal advice if you think your advance decision was ignored.

Healthcare professionals must follow your advance decision if:³²

- it exists,
- it is valid, and
- it applies to the particular situation.

How do professionals decide if an advance decision exists?

It is your responsibility to make sure that professionals are aware of your advance decision when it is needed.³³

See, [‘Where do I keep my advance statement or advance decision?’](#) for more information.

How do professionals decide if an advance decision is valid?

The advance decision must show that you made the document when:

- you were 18 or older, and
- you had mental capacity to make the advance decision.

An advance decision isn't valid if following apply.^{34,35}

- You withdrew the decision while you still had capacity to do so.
- After making the advance decision, you made a Lasting Power of Attorney (LPA) giving an attorney authority to make treatment decisions that are the same as those covered by the advance decision.
- You have done something that clearly goes against the advance decision which suggests that you have changed your mind.
- The treatment that you are being given is not the same treatment that you have written in your advance decision.
- The treatment that you are being given applies to a different circumstance than you have stated.
- There are reasonable grounds for believing that the situation has changed which you couldn't have known at the time of making your advance decision. And it is believed that this would have changed your advance decision if you'd have known.

How do professionals decide if an advance decision applies to a particular situation?

An advance decision must apply to the situation in question. And in the current circumstances.

Your healthcare professional needs to decide if you have capacity to accept or refuse treatment.³⁶ If you have capacity you can refuse treatment there and then without the need to look at your advance decision. You can also change your mind and accept treatment.

The advance decision must apply to the treatment that you are about to be offered. Your advance decision will not apply if:³⁷

- you are given different treatment to the one you have stated,
- the circumstances are different from those that you have stated, or
- there are reasonable grounds to believe that due to a change in your circumstances, you wouldn't have made the advance decision.

When professionals decide if your advance decision applies to the treatment you are about to be given healthcare professionals must think about the following.³⁸

- How long ago was the advance decision made?
- Have there been any changes in your personal life? Such as if you became pregnant since the advance decision was made.
- Have there been any medical developments which you couldn't have known about? Such as new medication.

Remember that your advance decision doesn't have to be followed if you are detained under the Mental Health Act. See [section 4](#) for more information.

You can find out more information about:

- Clinical negligence
- Legal advice
- Complaints

At www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Compassion in Dying

A national charity working to inform and empower people to exercise their rights and choices around end-of-life care.

Telephone: 0800 999 2434

Email: info@compassionindying.org.uk

Address: Compassion in Dying, 181 Oxford Street, London, W1D 2JT

Website: www.https://compassionindying.org.uk



¹ s4 Mental Capacity Act 2005 c9

² As note 1 (MCA 2005) s3

³ As note 1 (MCA 2005) s9

⁴ As note 1 (MCA 2005) s11

⁵ As note 1 (MCA 2005) s9(2)(c)

⁶ As note 1 (MCA 2005) s25(7)

⁷ National Institute for Clinical Excellence. *Information for the public: glossary*

<https://www.nice.org.uk/guidance/cg136/ifp/chapter/glossary#advance-statement> (accessed 29th January 2018)

⁸ As note 1 (MCA 2005) s24(1)

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- ⁹ Department for Constitutional Affairs. *Mental Capacity Act Code of Practice*. Para 9.12
- ¹⁰ As note 1 (MCA 2005) s24(1)
- ¹¹ As note 1 (MCA 2005) s3
- ¹² As note 1 (MCA 2005) s3(1)(d)
- ¹³ As note 1 (MCA 2005) s1(2)
- ¹⁴ Department of Health. *Mental Health Act Code of Practice*. Para 9.14
- ¹⁵ As note 14 para 9.9
- ¹⁶ s58A(5) Mental Health Act 1983 c20.
- ¹⁷ As note 16 (MHA 1983) s62(1A-1B).
- ¹⁸ As note 9 para 9.37
- ¹⁹ As note 9 para 9.10
- ²⁰ NHS Choices. *End of life care* <https://www.nhs.uk/Planners/end-of-life-care/Pages/advance-statement.aspx> (accessed 29th January 2018)
- ²¹ As note 9 para 9.19
- ²² As note 9 para 9.11
- ²³ As note 9 para 9.24
- ²⁴ As note 9 para 9.27
- ²⁵ As note 9 para para 9.38
- ²⁶ NHS digital. *Summary Care Records* <https://digital.nhs.uk/summary-care-records> (accessed 26th February 2018)
- ²⁷ As note 1 (MCA 2005) s24(3)
- ²⁸ As note 9 para 9.29
- ²⁹ As note 9 para 9.30
- ³⁰ As note 1 (MCA 2005) s24(3)
- ³¹ As note para 9.57.
- ³² As note 9 para 9.2
- ³³ As note 9 para 9.38
- ³⁴ As note 1 (MCA 2005) s25(2)
- ³⁵ As note 1 (MCA 2005) s25(4)
- ³⁶ As note 1 (MCA 2005) s25(3)
- ³⁷ As note 9 para 9.42
- ³⁸ As note 9 para 9.43

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This factsheet is available
in large print.



Rethink Mental Illness Advice Service

Phone 0300 5000 927

**Monday to Friday, 9:30am to 4pm
(excluding bank holidays)**

Email advice@rethink.org

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