What is this leaflet about?

This leaflet is about caring for and treating adults approaching the end of their life and the use of antibiotics during this time. It provides information to assist patients and their partners, families and carers when making choices about whether to start, or not to start, antibiotic treatment. Their healthcare professional team (which usually includes doctor(s), nurse(s), pharmacist) will help them to make these choices.

When a person is near the end of their life, giving an antibiotic to treat a new suspected infection may or may not make them feel better or live longer. We know that some people still wish to try antibiotic treatment, even if this means going back in to hospital. We also know that others prefer their symptoms to be treated in other ways.

What does end of life mean?
The last few days or weeks of life

What is antibiotic treatment?
Antibiotics are used to treat infections caused by some types of bacteria

This leaflet explains the following:

- making shared decisions about future care
- agreeing clear goals and expectations of the treatment
- reviewing whether antibiotic treatment should continue after it has been started

This leaflet is based on the Good Practice Recommendations on the Use of Antibiotics Towards the End of Life, produced by the Scottish Antimicrobial Prescribing Group (SAPG), for healthcare teams.

If you would like to see the version for clinical teams, please visit www.sapg.scot/media/5446/gprs-for-use-of-antibiotic-towards-eol.pdf
**Why is it important to make shared decisions about your future care?**

Evidence suggests that making shared decisions is the most important part of your care and also for your partner, family or carers. Your healthcare professional should listen to your wishes, discuss options for the future and help you to make choices. Your healthcare professional should write down these wishes in a document called an Anticipatory Care Plan (ACP). This plan is then shared with everyone caring for you so that people know what to do when there is a change in your health.

As part of planning ahead, your healthcare professional may wish to talk through what to do if you become unwell due to an infection.

This may include:

- Advising you of the potential benefits and risks of antibiotic treatment (see next section)
- Talking you through how antibiotic treatment may be taken
- Explaining to you how different antibiotic treatments may determine where you are cared for e.g. at home or in hospital
- Supporting you to think through how this fits in with what matters most to you

The discussion can also include your partner, family, carers or other people who are important to you. The ACP can be updated to reflect changes in your choices as time goes on.

If you are no longer able to make these decisions for yourself, your healthcare professional will try to speak with someone else close to you. You may have a Power of Attorney delegated to make decisions on your behalf but, if not, this may be your nearest relative, named person or guardian.

**Examples of antibiotic treatment are:**

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tablets, capsules or a liquid that you drink</strong></td>
<td>these can be used to treat most types of mild to moderate infections; they are taken by mouth and can be given at home.</td>
</tr>
<tr>
<td><strong>Injections</strong></td>
<td>these are used for more serious infections; they can be given as one-off injections or over time. If they need to be delivered through a drip directly into the bloodstream, you will usually be admitted to hospital.</td>
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</table>
Good Practice Recommendations for Use of Antibiotics Towards the End of Life

Why is it important to agree clear goals of antibiotic treatment?

Clear goals allow everyone involved in your care to think through and understand the reasons why a treatment decision has been made. Your healthcare professional will weigh up the reasons for starting and not starting antibiotic treatment and will discuss these with you.

They will take into account the following:

- Antibiotics should only be given if they are likely to be of overall benefit to the person.
- Towards the end of life, antibiotics are usually given to help symptoms related to infection. Sometimes, they are given to see whether infection can be cured.
- Not all infections need to be treated with antibiotics if a person is not experiencing significant symptoms.
- There are side-effects associated with antibiotics. The most common ones relate to the digestive system and affect 1 in 10 people. These include:
  - nausea and vomiting
  - bloating and indigestion
  - abdominal pain
  - loss of appetite
  - and severe diarrhoea (caused by a bacteria called C. difficile).
- There are other medicines that can also relieve symptoms caused by infection, e.g. painkillers, cough suppressants. There are other treatments that can relieve symptoms and may be helpful – for example, a hand held fan for laboured breathing (dyspnoea).
- Some symptoms, such as confusion (delirium), may be wrongly diagnosed as being caused by infection. These should be ruled out by the healthcare team before prescribing antibiotics.
- These issues will be considered by you and your healthcare professional(s) when deciding whether to start or not to start antibiotic treatment. Your healthcare professional should give you the opportunity to ask questions. Specialist palliative care doctors and nurses may be able to provide further expert support with these decisions.

What is a specialist palliative care doctor and nurse?

A healthcare professional who specialises in the treatment of symptoms and care of patients with terminal illness or approaching end of life.
Why is it important to review whether antibiotic treatment should continue, after it has been started?

After speaking with your healthcare professional, you may decide that starting antibiotic treatment is the right thing to do. People’s health can change quickly near the end of life – and people’s choices can change too. It is very important for your healthcare team to review your antibiotic treatment regularly to ensure that care continues to be right for you.

For example, your healthcare professional may suggest stopping antibiotic treatment:

- If it is not helping to treat your infection
- If it is causing side effects
- If you are becoming more unwell or close to the end of life

You can speak to your healthcare professional at any time to ask for antibiotic treatment to be stopped. Making this choice will not change how they think of you or how they care for you.

Where can I find out more information?

NHS Inform, Palliative care advice
www.nhsinform.scot/care-support-and-rights/palliative-care