

Myeloma

Information for the public

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www.nice.org.uk

About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

This information explains the advice about myeloma that is set out in NICE guideline NG35.

Information in the section on [blood clots \(thrombosis\)](#) was updated in 2018.

Does this information apply to me?

Yes, if you or someone you care for is over 16 and has or might have myeloma, smouldering myeloma or primary plasma cell leukaemia.

Myeloma

Myeloma (also called multiple myeloma) is a rare type of cancer that affects plasma cells,

causing too many to be produced in the bone marrow. Bone marrow is the tissue that makes blood cells. Plasma cells are a type of blood cell made by the bone marrow, and are part of the immune system (which stops you getting infections). Myeloma can develop anywhere there is bone marrow, so can affect lots of different bones in your body (for example, the spine, pelvis, ribs, and the long bones in your arms and legs).

Myeloma can cause anaemia (a shortage of red blood cells, which can make you feel tired all the time), pain and fractures in your bones, and can damage your kidneys. It can also make it easier for you to get infections, and harder for you to recover from them. There is no cure for myeloma, but there are treatments that can reduce the number of myeloma cells in your body, help with the symptoms and improve your quality and length of life.

This information also includes advice on 2 specific subtypes of myeloma: primary plasma cell leukaemia and smouldering myeloma.

Primary plasma cell leukaemia

Primary plasma cell leukaemia is a very rare subtype of myeloma, which happens when plasma cells affected by myeloma get into the blood. It causes many of the same symptoms, but [the treatments for it can be different](#).

Smouldering myeloma

Smouldering myeloma (which used to be called asymptomatic myeloma) is a subtype of myeloma that doesn't normally cause any symptoms. It can start causing symptoms and become myeloma over time, and if this happens it will need to be treated.

Because smouldering myeloma doesn't normally cause symptoms, it's not clear if treatment is helpful, or what information and support people with this condition need. However, your care team should still follow the advice given by NICE when [diagnosing smouldering myeloma](#), when doing any tests before you are diagnosed, and when [arranging follow-up checks with you](#).

Questions to ask about myeloma

- Can you tell me more about myeloma?

- Can you tell me more about my type of myeloma?
- Are there any support organisations? Are any of them in my local area?
- Can you provide any information for my family/carers?
- Where can I (and my family/carers) find more information?

Your care team

A range of professionals who specialise in different areas of treatment or support may be involved in your care. These could include haematologists (doctors who specialise in blood diseases), radiologists and radiotherapists (doctors and professionals who specialise in diagnosing and treating diseases using imaging technology such as X-rays), specialist nurses, pharmacists, psychologists (doctors who specialise in diagnosing and treating mental health problems), palliative care specialists (doctors and professionals who specialise in managing symptoms and caring for people at the end of their life), dietitians (professionals who specialise in diet), physiotherapists and occupational therapists (professionals who help you manage daily living activities), and other specialists depending on the symptoms you have (for example, specialists in kidney problems). All of these professionals will be trained and experienced in providing particular treatments or support.

Working with you

Your care team should talk with you about myeloma. They should explain any tests, treatments or support you should be offered so that you can decide together what is best for you. Your family or carer can be involved in helping to make decisions, but only if you agree. There are questions throughout this information that you can use to help you talk with your care team.

You may also like to read NICE's information for the public on [patient experience in adult NHS services](#). This sets out what adults should be able to expect when they use the NHS. We also have more information on the NICE website about [using health and social care services](#).

Some treatments or care described here may not be suitable for you. If you think that your treatment does not match this advice, talk to your care team.

Information and support

Your care team should tell you about your condition and any tests or treatments they are offering you. They should also talk to you about any support you need.

They should give you and your family members or carers information and support. You should also be offered psychological assessment and support (to help with anxiety or worries you have about myeloma) promptly if you need it. All this information and support should be available when you need it, and in particular:

- when you are diagnosed
- at the beginning and end of each treatment
- if the disease gets worse
- if you need to start end of life care (care for people in the last few months of their lives).

They should also tell you about:

- how myeloma is likely to affect you, and how it can go into remission and relapse
- what treatments you may be offered, including stem cell transplants if a transplant could help you
- the symptoms of myeloma and the side effects of the treatments you may have (such as infections and nerve damage [also called peripheral neuropathy])
- lifestyle changes you can make to reduce kidney and bone problems (such as fractures) caused by myeloma
- how to tell if you are getting new symptoms
- what support is available and how to find it, including how palliative care can help with the symptoms of myeloma.

Tests for myeloma

Diagnosis

Myeloma is diagnosed with blood tests, tests on your bone marrow, and [imaging tests](#).

To get a sample of your bone marrow, you will need to have a short procedure in hospital. You will be given a local anaesthetic and a small amount of your bone marrow will be taken (usually from your hip) with a needle. This bone marrow is tested so that your care team can confirm whether or not you have myeloma, and find out what kind of myeloma you have.

Imaging tests

Imaging tests for people who might have myeloma

If your care team think you might have myeloma or smouldering myeloma, they should offer you [imaging tests](#) to see if you have any problems with your bones (such as fractures or bones that are in danger of fracturing). What kind of test you have will depend on what is suitable for you and what you prefer.

- You will normally be offered an [MRI](#) scan first.
- If an MRI scan is unsuitable for you or you don't want it, you will normally be offered a [CT](#) scan.
- If MRI and CT scans are both unsuitable for you or you don't want either of them, you will normally be offered a [skeletal survey](#).

You should not be offered a test called an isotope bone scan to check for bone problems, because this test is less accurate than the ones listed above.

Imaging tests for people who have been diagnosed with myeloma or smouldering myeloma

If you had different imaging tests before you were diagnosed or haven't had scans of your whole body before, you may be offered an MRI, CT or [FDG PET-CT](#) scan of your whole

body when you are diagnosed with myeloma or smouldering myeloma. This is to check if the myeloma is damaging your bones or has spread to other parts of your body.

Myeloma can cause a problem with your spine called spinal cord compression. This can lead to pain and paralysis, and needs treating urgently. NICE has written separate information about [metastatic spinal cord compression](#), which has a different cause to the spinal cord compression caused by myeloma. However, the imaging tests and treatment for both kinds of spinal cord compression are the same, and your healthcare professionals should still follow this advice for people with myeloma.

Tests to find out more about your myeloma

Your care team will also offer you tests to find out more about your myeloma (called prognostic tests). Like the tests to diagnose myeloma, these will be blood and bone marrow tests. However, your care team should use the bone marrow they used to diagnose your myeloma for any prognostic tests, so that you don't have to have this procedure again.

Questions to ask about tests for myeloma

- Can you tell me more about the tests for myeloma? How many tests will I need to have?
- Will these tests cause any side effects?
- Where will I have these tests? Will I need to have them in hospital?
- How long will I have to wait until I have these tests?
- How long will it take to know if I have myeloma or not?
- Where can I (and my family/carers) find more information?

Initial treatment for myeloma

Myeloma can be treated with combinations of different chemotherapy medicines. Chemotherapy treatment will take place over several months. You may also be offered a

stem cell transplant, but this will be after your initial chemotherapy treatment (see [further treatment for myeloma](#) for more information on stem cell transplants). The choice of treatment will depend on which treatments might work best for you, your general health and fitness, and your preferences.

If a stem cell transplant is an option for you, you may be offered a medicine called bortezomib as your first myeloma treatment. Bortezomib is taken together with other medicines, so if you are offered bortezomib you will also be offered dexamethasone, or dexamethasone and thalidomide.

If a stem cell transplant is not right for you, you may be offered a medicine called thalidomide, together with other medicines. If thalidomide causes problems for you (such as side effects), you may be offered bortezomib, together with other medicines.

NICE has written separate information on when bortezomib and thalidomide can be used to treat myeloma. You can read the information on bortezomib [here](#), and the information on thalidomide [here](#).

Questions to ask about treatments for myeloma

- Why have you decided to offer me this particular type of treatment?
- What are the pros and cons of this treatment?
- What will it involve?
- How will it help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- How long will it take to have an effect?
- Will I have any problems if I don't take my medicine?
- Might I have problems when I have finished taking my medicine?
- Are there any risks with this treatment?
- Could you tell me more about what a stem cell transplant involves?
- What are the side effects of an autologous/allogeneic stem cell transplant?

- What are my options for taking treatments other than the one you have offered me?
- When should I start to feel better and what should I do if I don't start to feel better by then?
- Are there any clinical trials of new treatments I could try?
- Where can I (and my family/carers) find more information?

Treatment for primary plasma cell leukaemia

If you have primary plasma cell leukaemia, you may be offered chemotherapy as your first treatment, or you may be offered chemotherapy and an [autologous stem cell transplant](#).

Questions to ask about treatments for primary plasma cell leukaemia

- Why have you decided to offer me this particular type of treatment?
- What are the pros and cons of this treatment?
- What will it involve?
- How will it help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- How long will it take to have an effect?
- Will I have any problems if I don't take my medicine?
- Might I have problems when I have finished taking my medicine?
- Are there any risks with this treatment?

- Could you tell me more about what a stem cell transplant involves?
- What are the side effects of an autologous stem cell transplant?
- What are my options for taking treatments other than the one you have offered me?
- When should I start to feel better and what should I do if I don't start to feel better by then?
- Are there any clinical trials of new treatments I could try?
- Where can I (and my family/carers) find more information?

Further treatment for myeloma

If your myeloma has [relapsed](#), you may be offered bortezomib.

If you need treatment for myeloma symptoms after you have had at least 2 different courses of medicine, you may be offered a medicine called lenalidomide, together with dexamethasone.

NICE has written separate information on when bortezomib and lenalidomide can be used to treat relapsed myeloma. You can read the information on bortezomib [here](#), and the information on lenalidomide [here](#).

Stem cell transplants

You may be offered chemotherapy, followed by 1 of 2 different kinds of stem cell transplants: [autologous](#) or [allogeneic](#).

When deciding if either kind of transplant is a good option for you, your care team will check your general health and fitness (a transplant is riskier for people who are not in good health).

Autologous stem cell transplants

Your care team should not decide whether an autologous transplant is a good option for you based only on your age or how well your kidneys are working.

If you have had an autologous stem cell transplant already, you may be offered a second one. This will depend on:

- whether you're able to finish the chemotherapy given before the transplant, and how well this works
- how much your first transplant helped, and for how long
- how many other treatments you have had
- your general health and fitness, and whether you have any other conditions as well as myeloma
- how severe your myeloma is.

Allogeneic stem cell transplants

For allogeneic transplants, you and your care team should think about:

- whether your condition can be treated with chemotherapy
- how many myeloma treatments you have already had
- whether someone can donate stem cells to you (a donor)
- how the side effects of the transplant might be more difficult to deal with when you get older
- the potential risks and benefits of the transplant, and how well you understand these
- any other treatments that might help you instead.

Most people won't be offered an allogeneic stem cell transplant, as they are only a good option for a small number of people with myeloma. If an allogeneic transplant is an option for you, you may be offered it as part of a clinical trial. There is more information about clinical trials on [NHS Choices](#).

Kidney problems

Myeloma can cause problems with your kidneys. If it does, you may be offered bortezomib and dexamethasone together with other medicines to help with this.

If bortezomib is unsuitable for you (for example, because of side effects), you may be offered thalidomide and dexamethasone together with other medicines.

You should not be offered a procedure called 'plasma exchange' for kidney problems caused by myeloma, either on its own or together with other treatments. This is because it does not work as well as the treatments listed above, and doesn't help people more when used together with other treatments.

Off-label medicines

At the time of publication, thalidomide combined with dexamethasone is recommended for 'off-label' use when it is used to treat kidney problems caused by myeloma. Your doctor should tell you this and explain what it means for you.

In the UK, medicines are licensed to show that they work well enough and are safe enough to be used for specific conditions and groups of people. Some medicines can also be helpful for conditions or people they are not specifically for. This is called 'off-label' use. Off-label use might also mean the medicine is taken at a different dose or in a different way to the licence, such as using a cream or taking a tablet. There is more information about licensing medicines on [NHS Choices](#).

Questions to ask about kidney problems

- How can I tell if I'm starting to get kidney problems caused by myeloma?
- How long will I have to have treatments for my kidney problems?
- Will I have any problems if I don't take my medicine?
- Might I have problems when I have finished taking my medicine?
- Are there any risks with this treatment?

- Could you tell me more about off-label medicines?
- Are there any clinical trials of new treatments I could try?
- Where can I (and my family/carers) find more information?

Bone problems

Preventing bone problems from starting

Myeloma can damage your bones by causing too many plasma cells to be produced in the bone marrow, which can lead to pain and fractures. To reduce the chance of this happening, you should be offered a kind of medicine called a bisphosphonate. The exact one you take will depend on which works best for you and causes you the fewest side effects.

Rarely, bisphosphonates can cause a condition called osteonecrosis of the jaw. This can cause pain, swelling, infection and serious damage to your jaw. The risk is higher if you have any dental work (such as having a tooth removed) while taking bisphosphonates.

Having any dental work you need before you start myeloma treatment can lower your chance of jaw damage, so your care team may refer you to a dentist straightaway. This may not be possible if you need to start myeloma treatment urgently, but you should still be referred as soon as possible.

Treating problems in bones other than your spine

If you have bone problems and are not already taking a bisphosphonate, you should be offered one.

You may also be offered medical procedures, surgery and/or [radiotherapy](#) to treat bone problems.

If you start feeling pain again or a tumour in your bone regrows after you have had radiotherapy, you may be offered another course of radiotherapy to treat this.

Treating problems in your spine

If you have spine problems and are not already taking a bisphosphonate, you should be offered one. You should also be offered medicines to help with pain.

You may be offered surgery and/or radiotherapy to treat spine problems caused by myeloma. You may also be offered surgery and a back support (also called a brace) to help with pain.

Questions to ask about bone problems

- How can I tell if I'm starting to get bone problems caused by myeloma?
- How long will I have to take bisphosphonates?
- Will I have any problems if I don't take my medicine?
- Might I have problems when I have finished taking my medicine?
- How can I tell if I'm getting an infection in my jaw?
- Are there any risks with this treatment?
- Will I need to have an operation for my bone problems?
- Is there anything else you can give me to help with pain?
- Are there any clinical trials of new treatments I could try?
- Where can I (and my family/carers) find more information?

Other problems caused by myeloma

Infections

Myeloma and the treatments for it can damage your immune system. This can make it easier for you to get infections, and harder for you to recover from them. If you have myeloma, you should be offered the yearly flu jab (also called the influenza vaccination).

You may also be offered the pneumonia jab before you turn 65 (all people over 65 are already offered this).

Damage to your immune system means viruses can be worse when you get them. Depending on which myeloma treatments you are having, you may be offered medicines to help stop you getting some viruses (for example, chicken pox and shingles). Your care team may advise you to keep taking these after your myeloma treatment has finished. You may also be offered tests to see if you have certain viruses (for example, hepatitis B, hepatitis C or HIV) before you start myeloma treatment.

If you are having problems with your immune system or you keep getting infections, you may be offered treatment to help with this.

Nerve damage (peripheral neuropathy)

Some treatments for myeloma (such as bortezomib) can damage your nerves (particularly in your hands and feet), and this can cause pain and other problems. Your care team should tell you what symptoms to look out for, and encourage you to tell them if you have any of these or if they are getting worse.

If you get nerve damage, your care team may lower the dose of the medicine causing it. If you are taking bortezomib intravenously (through a drip into a vein), they may also start injecting it just underneath your skin instead.

If your nerve damage is getting worse, your care team should temporarily stop giving you the medicine that causes it.

Sometimes the symptoms of nerve damage can continue after you stop taking the medicine that caused them. If this happens and you still need medicine to treat your myeloma, your care team may offer you a medicine that is less likely to cause nerve damage.

Blood clots (thrombosis)

Blood clots form to stop you bleeding when you are injured (for example from a cut in your skin). However, some treatments for myeloma can cause your blood to clot inside your body, and this can block your veins and arteries. If the blood clot breaks away it can travel

through your blood to your lungs. This is called pulmonary embolism and it can be life-threatening.

To avoid this, you may be offered medicine to reduce the chance of your blood clotting inside your body. This will usually be aspirin or a medicine called an anticoagulant.

Fatigue

Myeloma and the treatments for it can make you feel very tired. There are lots of different causes for this, but if it is caused by anaemia (a shortage of red blood cells), you may be offered medicine to help your body produce more red blood cells.

Questions to ask about other problems caused by myeloma

General

- Are there any risks with this treatment?
- Where can I (and my family/carers) find more information?
- Will I have any problems if I don't take my medicine?
- Might I have problems when I have finished taking my medicine?
- Are there any clinical trials of new treatments I could try?

Infections

- How long will I have to take antiviral medicines?
- Why do you think I might have hepatitis/HIV?
- Could you tell me more about immunoglobulin replacement therapy?

Nerve damage

- How can I tell if I'm starting to get nerve damage?
- How long will I have to take medicines to help with the nerve damage?

- Is there anything else you can give me to help with pain?

Blood clots

- How can I tell if I'm starting to get blood clots caused by myeloma?
- How long will I have to take medicines to stop my blood from clotting?

Follow-up checks

If you have had treatment for myeloma and it is stable (not getting worse), you should have follow-up checks at least every 3 months to monitor your myeloma.

If you have smouldering myeloma you should also have follow-up checks every 3 months, but after 5 years your care team may discuss with you whether you need less or more regular check-ups.

Follow-up checks for myeloma and smouldering myeloma should include blood tests and checks to see if you are getting any symptoms. If your team think you may have new bone problems you may be offered [MRI](#), [CT](#) or [FDG PET-CT](#) scans.

Following up on your treatment

- How can I tell if my myeloma is becoming more active?
- How can I tell if my smouldering myeloma is becoming myeloma and needs treating?
- Where can I (and my family/carers) find more information?
- Are there any clinical trials of new treatments I could try?

Terms explained

Allogeneic stem cell transplant

A transplant of stem cells from another person's (a donor's) body to yours, after chemotherapy to treat your myeloma. In addition to killing myeloma cells, the chemotherapy kills the stem cells in your body. The transplant replaces these, and can help treat your myeloma as well. The donor will have been tested to see if their cells can be given to you safely.

Autologous stem cell transplant

When stem cells are collected from your body before you have chemotherapy, stored, and then given back to you afterwards. In addition to killing myeloma cells, the chemotherapy kills the stem cells in your body. The transplant replaces these. Using your own stem cells also avoids the immune system problems that can happen when using cells from somebody else's body.

Computed tomography (CT) scan

A test that uses X-rays to produce images of your bones.

Fluorodeoxyglucose positron emission tomography-computed tomography (FDG PET-CT) scan

A kind of CT scan in which you have an injection before the test starts. The injection contains a substance called a 'tracer' that can make it easier to see cancer cells on the test results.

Imaging tests

Scans that use technology such as X-rays and magnetic fields to produce an image of the inside of your body. Examples include CT scans and MRI scans.

Magnetic resonance imaging (MRI) scan

A test that uses magnetic fields to produce images of your bones.

Radiotherapy

Procedures that use radiation to destroy myeloma cells.

Relapse

When your myeloma symptoms come back after treatment. Myeloma can't be completely cured, and you can start having symptoms again even after several years without them.

Remission

When you stop having myeloma symptoms and there is only a low number of myeloma cells in your body. Myeloma can't be completely cured, but treatment can cause the symptoms to stop for periods of time.

Skeletal survey

A series of X-rays of most bones in your body.

Stem cells

Cells that can create the other types of cell in your body. The stem cells in your bone marrow are called haematopoietic stem cells, and create all your blood cells.

Sources of advice and support

- Bloodwise, 0808 2080 888
www.bloodwise.org.uk
- Cancer Research UK, 0808 800 4040
www.cancerresearchuk.org

- Leukaemia Care, 0808 801 0444
www.leukaemiacare.org.uk
- Macmillan Cancer Support, 0808 808 0000
www.macmillan.org.uk
- Myeloma UK, 0800 980 3332
www.myeloma.org.uk

You can also go to [NHS Choices](#) for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

Other NICE guidance

- [Pomalidomide for relapsed and refractory multiple myeloma previously treated with lenalidomide and bortezomib](#) (2015) NICE technology appraisal guidance 338
- [Neuropathic pain in adults: pharmacological management in non-specialist settings](#) (2013) NICE guideline CG173
- [Osteoporosis: assessing the risk of fragility fracture](#) (2012) NICE guideline CG146
- [Palliative care for adults: strong opioids for pain relief](#) (2012) NICE guideline CG140
- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- [Bortezomib and thalidomide as first treatments for multiple myeloma](#) (2011) NICE technology appraisal guidance 228
- [Lenalidomide for multiple myeloma in people who have had previous treatment](#) (2009) NICE technology appraisal guidance 171
- [Metastatic spinal cord compression in adults: diagnosis and management](#) (2008) NICE guideline CG75
- [Bortezomib monotherapy for relapsed multiple myeloma](#) (2007) NICE technology appraisal guidance 129

- [Improving outcomes in children and young people with cancer](#) (2005) NICE cancer service guidance 7
- [Improving outcomes in haematological cancers](#) (2003) NICE cancer service guidance 3

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