

YOUR PATIENT DIARY



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Your patient diary

A diagnosis of myeloma affects everyone differently. Feeling a mix of emotions is very common and are a natural part of coming to terms with a diagnosis.

Keeping a diary can help to clarify your thoughts and feelings and can provide a useful record of your test results and treatment.

This diary has been designed to do just that; to give you a place to write down your thoughts, how you are feeling and any questions you may have. It will help you stay informed and keep track of important information related to your myeloma and its treatment.

It may also help you and your healthcare team to communicate more easily about your myeloma, your treatment and any questions or concerns that you may have.

Keep your diary handy and record questions and new information as soon as you can. Remember to take it with you every time you visit your doctor, nurse or other healthcare professional.

How to use this diary

Some sections are designed for you to fill in; others should be filled in by your healthcare team.

If you have any questions or concerns about the details your healthcare team fill in, ask them to explain, or write down your questions in the 'Questions and notes' section to ask at your next appointment.

Be reassured that it is common to have concerns and questions. Doctors and nurses are used to talking to patients about many myeloma-related issues.



Contact details





Contact details

Use this section to keep a record of your details, your emergency contact and your healthcare team's details.

You may want to ask your doctor and/or nurse to fill in your healthcare team's details. It's particularly important to make sure you have a record of who to contact for out-of-hours advice.



My details

Name

Address

Telephone (Home)

Telephone (Work)

Mobile

Email address

NHS number (if known)

Preferred language

Who to contact in an emergency

Name

Relationship to patient

Telephone (Home)

Telephone (Work)

Mobile

Notes

My healthcare team's contact details

GP

Name

Location

Telephone

Consultant haematologist

Name

Location

Telephone

Nurse specialist/key worker

Name

Location

Telephone

Social worker

Name

Location

Telephone

Occupational therapist

Name

Location

Telephone

Physiotherapist

Name

Location

Telephone

 Dietitian

Name

Location

Telephone

Others involved in your care

Occupation

Name

Location

Telephone

 In case you need advice out-of-hours

Your consultant or nurse should provide you with the contact details of the out-of-hours doctor on call at your hospital.

Contact name

Telephone

 **Call NHS 111 by dialling 111** (England, Scotland and Wales)

 **Visit [nidirect.gov.uk](https://nhs.uk/nidirect)** (Northern Ireland)

My medical history

Date of birth

Previous medical history (e.g. diabetes, asthma)

Regular medication(s)

Allergies

My myeloma diagnosis

Date of myeloma
diagnosis

Name of consultant who
made the diagnosis

Hospital

Myeloma type (tick)

☐ IgG☐ IgE☐ Non-secretory☐ IgA☐ IgM☐ Smouldering☐ IgD☐ Light chain☐ Don't know

Contact details

Myeloma Support Groups welcome patients, their families, friends and carers in an informal setting to provide information and support.

They give those affected by myeloma the opportunity to discuss, learn and share with others in a similar situation and from the same area.

My local Myeloma Support Group details

Name

Location

Venue

Leader name

Telephone

Email address



Information about support groups in your area

Find your nearest support group by visiting the Myeloma UK website at myeloma.org.uk/support-groups

 Contact details

Contact Myeloma UK

Get in touch for free information, emotional support and practical advice. We're here to answer your questions and concerns.

Myeloma Infoline

0800 980 3332

Ask the Nurse

AskTheNurse@myeloma.org.uk

Website

myeloma.org.uk



Any other contacts

Note the details of any other contacts in the space below.



Appointments





Appointments

Use this section to keep a record of your appointments.

You can keep note of the reason for each appointment, such as a scan, blood test, urine test or general follow-up.

You may find it useful to prepare for your upcoming appointments by writing questions you would like to ask your healthcare team. You can also write notes on what was discussed during your appointments.

Practical tips for getting the most out of your appointments:

- Keep an ongoing list of questions between appointments to ask your healthcare team next time you see them
- Appointments can be stressful and you may have to absorb a lot of information. Bring a pen and some extra paper to take notes
- Bring a family member or friend who can take notes and be an extra listening ear
- Try to describe symptoms as accurately as possible (think: what, where and when)
- Don't be afraid to ask for extra time to make a decision about treatment options
- Appointments can be delayed or overrun. Try to keep this in mind when planning your day



Appointments

Date

Time

Who it's with

Location

Reason for
appointment
(e.g. follow-up, X-ray,
blood test, etc.)

Notes
(questions to
ask, what was
discussed, etc.)

Date

Time

Who it's with

Location

Reason for
appointment
(e.g. follow-up, X-ray,
blood test, etc.)

Notes
(questions to
ask, what was
discussed, etc.)



Appointments

Date

Time

Who it's with

Location

Reason for
appointment
(e.g. follow-up, X-ray,
blood test, etc.)

Notes
(questions to
ask, what was
discussed, etc.)



Date

Time

Who it's with

Location

Reason for
appointment
(e.g. follow-up, X-ray,
blood test, etc.)

Notes
(questions to
ask, what was
discussed, etc.)





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appointment
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ask, what was
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Appointments

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ask, what was
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Location

Reason for
appointment
(e.g. follow-up, X-ray,
blood test, etc.)

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(questions to
ask, what was
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(e.g. follow-up, X-ray,
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Appointments

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Time

Who it's with

Location

Reason for
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(e.g. follow-up, X-ray,
blood test, etc.)

Notes
(questions to
ask, what was
discussed, etc.)



Date

Time

Who it's with

Location

Reason for
appointment
(e.g. follow-up, X-ray,
blood test, etc.)

Notes
(questions to
ask, what was
discussed, etc.)



Blood test results





Blood test results



Regularly monitoring your blood is one of the many ways used to help provide a picture of your myeloma so that you and your healthcare team can determine the best treatment options for you.

Use this section to record the results from your blood tests. You may find it helpful to ask your doctor or nurse to fill in this section.

If you have any questions or concerns about the details they fill in, ask your doctor or nurse to explain, or write down your questions in the 'Questions and notes' section of this diary to ask at your next appointment.



For more information see the **Tests and investigations in myeloma Infoguide** from Myeloma UK

You will have regular blood tests to monitor your myeloma and to check the levels of different types of blood cells and blood chemicals.

Protein tests



Antibodies (also known as immunoglobulins) are proteins in the blood that are produced by the immune system to help fight infection. Paraprotein is an abnormal antibody produced by myeloma cells and has no useful function. The levels of paraprotein in the blood indicate how active your myeloma is and how you are responding to treatment.

Full blood count

Different types of blood cells have different functions in the body. A full blood count measures the numbers of these different cells in your blood. In myeloma, the myeloma cells affect the production of normal blood cells, so the levels of these cells may be lower than normal.

Blood chemistry tests



Blood contains a number of different chemicals. Different diseases can cause the levels of these chemicals to change. For example, high levels of urea can indicate that the kidneys are not working properly. High levels of calcium (known as hypercalcaemia) can indicate active myeloma bone disease.

Normal ranges for these measurements can be found in the reference table on the next page. Exact ranges can vary slightly between hospital laboratories; so the numbers in this table are for guidance only.



Blood test results

Reference table: normal blood measurements

Blood test	Measurement	Normal range	Notes
Proteins	Paraprotein	0 g/L	Abnormal protein found in certain conditions, including myeloma
	Kappa (κ) light chain	3.3–19.4 mg/L	Part of an immunoglobulin (antibody). Levels are often raised in myeloma, with an abnormal ratio
	Lambda (λ) light chain	5.7–26.3 mg/L	
	Kappa (κ)/Lambda (λ) ratio	0.26–1.65	
Full blood count	Albumin	35–50 g/L	Often lowered in myeloma because of activity of myeloma cells
	Haemoglobin (Hb) (men)	135–180 g/L	A low haemoglobin (Hb) causes anaemia and fatigue
	Haemoglobin (Hb) (women)	115–160 g/L	
	White blood cells (WBC)	4.0–11.0 x10 ⁹ /L	A low white blood cell count increases your risk of infection
Blood chemistry	Platelets (Pl)	150–440 x10 ⁹ /L	A low platelet count increases your risk of bruising and bleeding
	Absolute neutrophil count (ANC)	2.0–7.5 x10 ⁹ /L	A low count makes you less able to fight infection
	Urea	2.5–6.7 mmol/L	Often raised when kidneys are not working properly
	Estimated glomerular filtration rate (eGFR)	90 ml/min or above	Often lowered when kidneys are not working properly
	Calcium	2.1–2.65 mmol/L	Raised by myeloma bone disease



1000000

1001

 $\sum$ $\lambda:$

Ratio:

Hb:

WBC:

P 11

ANC:

Urea:

eGFR:

9

1

Infoline 0800 980 3332

Date													
Paraprotein level													
Light chains													
Full blood count													
Kidney function													
Other (i.e. calcium, albumin)													





1000000

1001

 $\sum$ $\lambda:$

Ratio:

Hb:

WBC:

P 11

ANC:

Urea:

eGFR:

9

(i.e. calcium, albumin)



Date													
Paraprotein level													
Light chains													
Full blood count													
Kidney function													
Other (i.e. calcium, albumin)													





1000000

1001

 $\sum$ $\lambda:$

Ratio:

Hb:

WBC:

P 11

ANC:

Urea:

eGFR:

9

Infoline 0800 980 3332

Date													
Paraprotein level													
Light chains													
Full blood count													
Kidney function													
Other (i.e. calcium, albumin)													



Treatment record





Treatment record



Use this section to help keep all your treatment information together in one place.



Ask your doctor or nurse to fill in the following record with your treatment to help you make sure you are taking your treatment as advised. You can record any treatments that aim to treat the myeloma, as well as any supportive treatments which aim to manage the symptoms or complications of myeloma.



You may be prescribed a combination of different anti-myeloma treatments to be taken at different times and in different ways. It may help to record each of these treatments in separate entries.

If you are experiencing any side effects of your myeloma treatment, make sure to discuss these with your healthcare team. You can keep a record of these in the 'Symptoms and side effects record' section.

If you have any questions or concerns about the information completed by your healthcare team, ask them to explain it, or you can write them down in the 'Questions and notes' section of this diary to ask at your next appointment.

Myeloma UK provides free publications on a wide range of topics, including myeloma treatments.

Download or order them from our website



myeloma.org.uk/publications

Order them via the Infoline



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Myeloma is highly treatable in most patients. A large number of anti-myeloma treatments and combinations are now available, which can be used at different stages of your myeloma, even when you have had several previous treatments.

○ Myeloma is known as a relapsing and remitting cancer. This means there are periods when the myeloma is active and needs to be treated, followed by periods of remission or plateau where the myeloma may not be treated. The myeloma can then relapse and will need to be treated again.

Remissions can last for long periods of time, and many patients have a number of remissions and relapses during their lifetime.

Your myeloma treatment will aim to do a number of things, such as:

- Control the growth of the myeloma
- Relieve the complications myeloma causes
- Improve your level of comfort, enjoyment and ability to pursue daily activities (your quality of life)

Treatment is often with combinations of drugs that work together, including chemotherapy, steroids, and specific anti-myeloma drugs.

○ The drugs are given in a set pattern over a period of time known as a cycle, which may last from weeks to months. A series of cycles is known as a course or line of treatment. This is why your healthcare team may refer to your treatment as 'first line', and then following treatments as 'second line', then 'third line' and so on.

Some drugs are given for a set number of cycles. Other drugs are continued through your remission or plateau, until your myeloma is beginning to come back, or until side effects mean treatment has to be stopped.

You are also likely to be given supportive treatments, which don't treat the myeloma directly, but can help you with side effects and complications of myeloma or treatment. You can use this space to keep a record of these too.



For further information and support see the **Infopack for relapsed and/or refractory myeloma patients** from Myeloma UK



Supplements or herbal medicines that have not been prescribed by your haematologist may cause harm when taken alongside your prescribed treatment.

You must speak to your healthcare team before taking any kind of supplement or alternative treatment, including herbal, traditional or natural medicines and remedies, and vitamins or wellbeing supplements, to ensure it is safe to do so.

Treatment record

Treatment name

Date treatment prescribed

Line of treatment

(e.g. first line, second line, etc.)

Dose

Where I have it

(e.g. at home, in hospital)

When I have it

(days of the week or month, time of day)

How I have it

(e.g. with food, on an empty stomach)

Treatment end date

Treatment name

Date treatment prescribed

Line of treatment

(e.g. first line, second line, etc.)

Dose

Where I have it

(e.g. at home, in hospital)

When I have it

(days of the week or month, time of day)

How I have it

(e.g. with food, on an empty stomach)

Treatment end date

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(e.g. at home, in hospital)

When I have it

(days of the week or month, time of day)

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(e.g. with food, on an empty stomach)

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Treatment record

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(e.g. at home, in hospital)

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Treatment end date

Treatment name

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(e.g. with food, on an empty stomach)

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Line of treatment

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Where I have it

(e.g. at home, in hospital)

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(e.g. at home, in hospital)

When I have it

(days of the week or month, time of day)

How I have it

(e.g. with food, on an empty stomach)

Treatment end date

Treatment name

Date treatment prescribed

Line of treatment

(e.g. first line, second line, etc.)

Dose

Where I have it

(e.g. at home, in hospital)

When I have it

(days of the week or month, time of day)

How I have it

(e.g. with food, on an empty stomach)

Treatment end date

Vaccination record





Vaccination record

Because myeloma can weaken your immune system, it is important for people living with myeloma to stay up to date with their vaccinations.

You can use this section to keep a record of your vaccinations.



For more information about vaccination in myeloma, as well as a list of recommended vaccines, see the **Vaccines and myeloma Infosheet** from Myeloma UK



Vaccination record

Vaccination

Date

Time

Notes

Vaccination

Date

Time

Notes

Vaccination

Date

Time

Notes

Vaccination

Date

Time

Notes



Vaccination record

Vaccination

Date

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Vaccination record

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Vaccination

Date

Time

Notes

Vaccination

Date

Time

Notes

Vaccination

Date

Time

Notes

Symptoms and side effects record





Symptoms and side effects record

You may have a range of complications caused by the myeloma itself or side effects of treatment. It can be very difficult to determine which are caused by your myeloma and which are caused by your treatment because there is often overlap between the two.

Keep a record and always report any symptoms and side effects to your healthcare team as soon as possible. They will assess how you are feeling and make any necessary adjustments to your treatment to reduce the side effects. If your treatment dose is reduced it does not necessarily mean your treatment will be less effective.

Remember to record your symptoms and side effects as soon as possible. Write down your symptoms and side effects even if you are not sure if they are from your myeloma, your treatment or are happening for another reason. This will help to keep your record accurate and will make discussions with your healthcare team easier.

Myeloma UK provides free publications on a wide range of topics, including symptoms and side effects of myeloma and its treatment.

Download or order them from our website



myeloma.org.uk/publications

Order them via the Infoline



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Symptoms and side effects record

The following sections provide space for you to record how you feel. They cover the most common symptoms and side effects, as well as giving space to record anything else affecting you:



Fatigue

an extreme tiredness or lack of energy that is not relieved by rest or sleep



Pain

e.g. in your back, hips, ribs or shoulders



Peripheral neuropathy

numbness, tingling, increased sensitivity and pain in your hands and feet



Gut problems

constipation, diarrhoea, nausea and vomiting



Psychological wellbeing

how you feel, your mental and emotional wellbeing



Any other symptoms or side effects

e.g. dizziness, confusion, headaches, changes to urine (colour, quantity) and infections



Symptoms and side effects record



If you experience any of the symptoms listed on this page, you must seek urgent medical help. For non-urgent medical attention please contact your doctor or nurse as soon as possible or refer to your out-of-hours contact recorded in the 'Contact details' section.

Call 999 immediately if you develop any of the following:

Symptoms of spinal cord compression, which can cause permanent nerve damage:

- Tingling, loss of sensation or shooting pain in your arms or legs
- Limb weakness
- Difficulty controlling your bladder or bowel
- Spinal pain that is aggravated by going to the toilet, coughing or sneezing

Symptoms of a blood clot or deep vein thrombosis:

- Pain, tenderness or swelling in one of your calves which may also feel hot to the touch
- Red skin, e.g. on the back of your calf
- Chest pain
- Sudden shortness of breath

Symptoms of sepsis, also called blood poisoning or septicaemia:

- A high temperature (fever) of 37.5°C or above
- Extreme shivering or muscle pain
- Feeling extremely unwell
- Breathing very fast or feeling breathless
- Slurred speech or confusion



Fatigue



Symptoms and side effects record





Fatigue

Fatigue is a feeling of extreme tiredness, lethargy or exhaustion, experienced all or most of the time. Fatigue is different from the everyday tiredness that comes with the demands of daily life.

It is an overwhelming exhaustion that is not relieved by sleep or rest and can affect you physically, psychologically and emotionally.

Fatigue can be a complication of the myeloma itself or it can be a side effect of treatment. Fatigue is very common and affects over 70% of myeloma patients at some point. Living with fatigue can be extremely challenging as it can affect all areas of your life.

Accurately recording your fatigue can help you communicate how you are feeling to your healthcare team. It can also help to show you whether your fatigue is improving over time. Record your fatigue and its effects in the following tables using the scale:

0

Not at all

1

A little bit

2

Somewhat

3

Quite a bit

4

Very much



For more information see the **Fatigue and myeloma Infoguide** from Myeloma UK

 Fatigue
Date**Time**

Too tired to eat ☐0 ☐1 ☐2 ☐3 ☐4Feel fatigued ☐0 ☐1 ☐2 ☐3 ☐4Need help doing my usual activities ☐0 ☐1 ☐2 ☐3 ☐4Feel weak ☐0 ☐1 ☐2 ☐3 ☐4Frustrated by being too tired to do the things I want to do ☐0 ☐1 ☐2 ☐3 ☐4Need to sleep during day ☐0 ☐1 ☐2 ☐3 ☐4**Date****Time**

Too tired to eat ☐0 ☐1 ☐2 ☐3 ☐4Feel fatigued ☐0 ☐1 ☐2 ☐3 ☐4Need help doing my usual activities ☐0 ☐1 ☐2 ☐3 ☐4Feel weak ☐0 ☐1 ☐2 ☐3 ☐4Frustrated by being too tired to do the things I want to do ☐0 ☐1 ☐2 ☐3 ☐4Need to sleep during day ☐0 ☐1 ☐2 ☐3 ☐4**Date****Time**

Too tired to eat ☐0 ☐1 ☐2 ☐3 ☐4Feel fatigued ☐0 ☐1 ☐2 ☐3 ☐4Need help doing my usual activities ☐0 ☐1 ☐2 ☐3 ☐4Feel weak ☐0 ☐1 ☐2 ☐3 ☐4Frustrated by being too tired to do the things I want to do ☐0 ☐1 ☐2 ☐3 ☐4Need to sleep during day ☐0 ☐1 ☐2 ☐3 ☐4**Date****Time**

Too tired to eat ☐0 ☐1 ☐2 ☐3 ☐4Feel fatigued ☐0 ☐1 ☐2 ☐3 ☐4Need help doing my usual activities ☐0 ☐1 ☐2 ☐3 ☐4Feel weak ☐0 ☐1 ☐2 ☐3 ☐4Frustrated by being too tired to do the things I want to do ☐0 ☐1 ☐2 ☐3 ☐4Need to sleep during day ☐0 ☐1 ☐2 ☐3 ☐4

Fatigue

Date

Time

Feel fatigued

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Feel weak

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need to sleep during day

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Too tired to eat

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need help doing my usual activities

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Frustrated by being too tired to do the things I want to do

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Date

Time

Feel fatigued

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Feel weak

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need to sleep during day

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Too tired to eat

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need help doing my usual activities

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Frustrated by being too tired to do the things I want to do

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Date

Time

Feel fatigued

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Feel weak

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need to sleep during day

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Too tired to eat

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need help doing my usual activities

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Frustrated by being too tired to do the things I want to do

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Date

Time

Feel fatigued

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Feel weak

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need to sleep during day

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Too tired to eat

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need help doing my usual activities

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Frustrated by being too tired to do the things I want to do

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

 Fatigue
Date**Time**Too tired to eat ☐0 ☐1 ☐2 ☐3 ☐4Feel fatigued ☐0 ☐1 ☐2 ☐3 ☐4Need help doing my usual activities ☐0 ☐1 ☐2 ☐3 ☐4Feel weak ☐0 ☐1 ☐2 ☐3 ☐4Frustrated by being too tired to do the things I want to do ☐0 ☐1 ☐2 ☐3 ☐4Need to sleep during day ☐0 ☐1 ☐2 ☐3 ☐4**Date****Time**Too tired to eat ☐0 ☐1 ☐2 ☐3 ☐4Feel fatigued ☐0 ☐1 ☐2 ☐3 ☐4Need help doing my usual activities ☐0 ☐1 ☐2 ☐3 ☐4Feel weak ☐0 ☐1 ☐2 ☐3 ☐4Frustrated by being too tired to do the things I want to do ☐0 ☐1 ☐2 ☐3 ☐4Need to sleep during day ☐0 ☐1 ☐2 ☐3 ☐4**Date****Time**Too tired to eat ☐0 ☐1 ☐2 ☐3 ☐4Feel fatigued ☐0 ☐1 ☐2 ☐3 ☐4Need help doing my usual activities ☐0 ☐1 ☐2 ☐3 ☐4Feel weak ☐0 ☐1 ☐2 ☐3 ☐4Frustrated by being too tired to do the things I want to do ☐0 ☐1 ☐2 ☐3 ☐4Need to sleep during day ☐0 ☐1 ☐2 ☐3 ☐4**Date****Time**Too tired to eat ☐0 ☐1 ☐2 ☐3 ☐4Feel fatigued ☐0 ☐1 ☐2 ☐3 ☐4Need help doing my usual activities ☐0 ☐1 ☐2 ☐3 ☐4Feel weak ☐0 ☐1 ☐2 ☐3 ☐4Frustrated by being too tired to do the things I want to do ☐0 ☐1 ☐2 ☐3 ☐4Need to sleep during day ☐0 ☐1 ☐2 ☐3 ☐4

Fatigue

Date

Time

Feel fatigued

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Feel weak

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need to sleep during day

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Too tired to eat

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need help doing my usual activities

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Frustrated by being too tired to do the things I want to do

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Date

Time

Feel fatigued

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Feel weak

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Need to sleep during day

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Too tired to eat

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Frustrated by being too tired to do the things I want to do

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Frustrated by being too tired to do the things I want to do

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4



Pain



Symptoms and side effects record





Pain



Accurately recording your pain is a key part of effective pain management.

Record your pain regularly in the following tables using the scale where:



0

No pain

10

Worst pain, as bad
as you can imagine

If pain is a common side effect for you or is not managed well, you might want to consider recording your pain score immediately before, and 30 minutes after, taking your pain treatment, using the scale as a guide on how to rate your pain.

Use this record of your pain when you see your doctor to show whether your painkillers are effectively controlling your pain or not.



For more information, see the **Pain and myeloma Infoguide** from Myeloma UK



Pain

Date	Time	Description (location, stabbing, aching, etc.)	Pain rating										
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10

 Pain

Date	Time	Description (location, stabbing, aching, etc.)	Pain rating										
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10





Pain

Date	Time	Description (location, stabbing, aching, etc.)	Pain rating										
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10

 Pain

Date	Time	Description (location, stabbing, aching, etc.)	Pain rating										
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10





Pain

Date	Time	Description (location, stabbing, aching, etc.)	Pain rating										
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10

 Pain

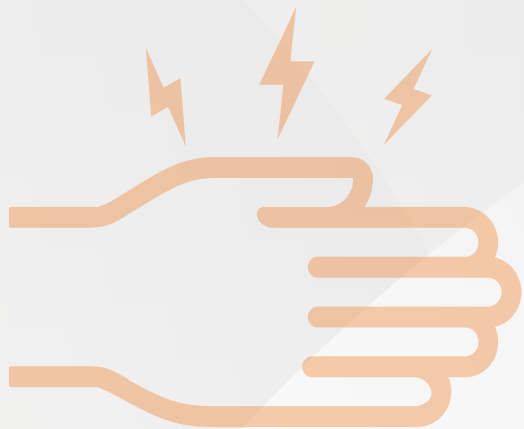
Date	Time	Description (location, stabbing, aching, etc.)	Pain rating										
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10
			0	1	2	3	4	5	6	7	8	9	10





Peripheral neuropathy

Symptoms and side effects record





Peripheral neuropathy



Peripheral neuropathy is the term used to describe damage to the nerves that transmit signals such as pain and touch, or that sense our position and control movement.



Some treatments can cause peripheral neuropathy, as can the myeloma itself. The nerves most commonly affected are those of the hands, lower legs and feet.

This damage causes:



- Pins and needles
- Tingling or numbness
- Altered feeling, pain and/or sensitivity

Peripheral neuropathy can get progressively worse, so it is very important to report any of these symptoms to your doctor.



For more information see the **Peripheral neuropathy Infosheet** from Myeloma UK



Peripheral neuropathy

Record your peripheral neuropathy in the following tables using the scale 0–3, where:

0 None	1 Mild Doesn't interfere with your ability to do your daily activities	2 Moderate Makes it difficult doing daily activities, such as: • Preparing meals • Shopping for groceries • Handling money	3 Severe Makes it difficult to, or prevents you from being able to: • Take a shower or bath • Get dressed and undressed • Take treatments • Eat
------------------	---	---	--



Peripheral neuropathy

Other notes (e.g. difficulty holding a spoon, difficulty fastening shirt buttons, feeling off balance. Are your symptoms better, worse, or the same as before?)

Severity
Rating

Date		0	1	2	3	
Time						

Date		0	1	2	3	
Time						

Date		0	1	2	3	
Time						

Date		0	1	2	3	
Time						

Date		0	1	2	3	
Time						





Peripheral neuropathy

Other notes (e.g. difficulty holding a spoon, difficulty fastening shirt buttons, feeling off balance. Are your symptoms better, worse, or the same as before?)

Severity
Rating

Date

Time

0 1 2 3

Date

Time

0 1 2 3

Date

Time

0 1 2 3

Date

Time

0 1 2 3

Date

Time

0 1 2 3



Peripheral neuropathy

Other notes (e.g. difficulty holding a spoon, difficulty fastening shirt buttons, feeling off balance. Are your symptoms better, worse, or the same as before?)

Severity
Rating

Date		0	1	2	3	
Time						

Date		0	1	2	3	
Time						

Date		0	1	2	3	
Time						

Date		0	1	2	3	
Time						

Date		0	1	2	3	
Time						





Peripheral neuropathy

Other notes (e.g. difficulty holding a spoon, difficulty fastening shirt buttons, feeling off balance. Are your symptoms better, worse, or the same as before?)

Severity
Rating

Date

Time

0 1 2 3

Date

Time

0 1 2 3

Date

Time

0 1 2 3

Date

Time

0 1 2 3

Date

Time

0 1 2 3



Peripheral neuropathy

Other notes (e.g. difficulty holding a spoon, difficulty fastening shirt buttons, feeling off balance. Are your symptoms better, worse, or the same as before?)

Severity
Rating

Date

Time

0

1

2

3

Date

Time

0

1

2

3

Date

Time

0

1

2

3

Date

Time

0

1

2

3

Date

Time

0

1

2

3





Gut problems



Symptoms and side effects record





Gut problems



Constipation, diarrhoea, nausea and vomiting are all common side effects of myeloma treatment, and can have a significant impact on quality of life.



Recording these symptoms can help you explain to your doctor how they are affecting your quality of life. An accurate record can also be useful when trying to determine the cause of these symptoms.



If you feel constipated, have diarrhoea, vomiting, nausea or loss of appetite, refer to the scales on the next page and then make a note of it in the tables.



For more information about gut problems (gastrointestinal disturbances), see the **Gastrointestinal disturbances Infosheet** from Myeloma UK





Gut problems

Constipation

0

None

1

Happens occasionally, sometimes use stool softeners, laxatives or alter diet

2

Regularly using laxatives or enemas. Interferes with your daily activities like preparing meals, going shopping and social occasions

3

Not able to pass any stool or gas. Interferes with your ability to take care of yourself: you may be less able to shower, eat and get dressed

Diarrhoea

0

None

1

More than four bowel movements per day

2

4–6 bowel movements per day

3

7 or more bowel movements per day, loss of bowel control. Interferes with your ability to take care of yourself: you may be less able to shower, eat and get dressed

Nausea

0

None

1

Loss of appetite, but eating habits unchanged

2

Eating less, but haven't lost much weight

3

Unable to eat or drink, losing weight

Vomiting

0

None

1

1–2 times a day

2

3–5 times in 24 hours

3

6 or more times in 24 hours



Gut problems

Date	Time	Constipation	Diarrhoea	Nausea	Vomiting
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3





Gut problems



Date	Time	Constipation	Diarrhoea	Nausea	Vomiting
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3

 Gut problems

Date	Time	Constipation	Diarrhoea	Nausea	Vomiting
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3





Gut problems

[illegible]



Gut problems

Date	Time	Constipation	Diarrhoea	Nausea	Vomiting
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
		0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3





Psychological wellbeing

Symptoms and side effects record





Psychological wellbeing



Although it can be common to focus mainly on your physical health, your mental health is important too. Your healthcare team is there to support all aspects of living with myeloma. It's normal to have ups and downs, but it's important to get the support you need when life is challenging and you're not feeling positive or mentally and emotionally well.

You can use this record to keep a track of how you're feeling. It may help to make a note of what is making you feel that way, if you know of a reason, and what, if anything, has helped you feel better.

It might help to think about how often you:

- Feel nervous, anxious or on edge
- Can't stop worrying or control your worrying
- Have difficulty concentrating
- Feel restless or unable to sit still
- Get easily annoyed or irritated
- Feel afraid, as if something awful might happen
- Have negative thoughts
- Feel down, depressed or hopeless
- Have an altered appetite – eating more or less than normal
- Lose interest in things you used to enjoy



If you are feeling distressed, in a state of despair, as though you may hurt yourself, suicidal or in need of immediate emotional support, call NHS 111 or visit [nhs.uk](https://www.nhs.uk) for local support services. Samaritans also offer a free, 24 hour helpline you can call on 116 123.



Psychological wellbeing

Myeloma UK provides information and support to help you with your psychological wellbeing. You can find out more in the 'Help and support' section of this diary.



Myeloma UK has an emotional wellbeing tool, which is an interactive digital tool designed to help support wellbeing. The tool gives you space to work through how you're feeling, and find strategies and sources of support to help you. Access the emotional wellbeing tool at myeloma.org.uk/wellbeing



Psychological wellbeing

Date

Time

How I feel

Date

Time

How I feel



Date

Time

How I feel

Date

Time

How I feel



Date

Time

How I feel



Psychological wellbeing

Date

Time

How I feel

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Psychological wellbeing

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Date

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How I feel



Other symptoms and side effects

Symptoms and side effects record





Other symptoms and side effects



Use the following tables to record any other symptoms and side effects that are affecting you. This may include dizziness, confusion, headaches, insomnia, changes to urine (colour, quantity), and infections.



For each symptom or side effect make a note of:

- How you feel – e.g. tightness in chest, lost balance
- How long you feel like that – e.g. three days, two minutes
- What helps to ease it – e.g. sitting down, eating, fresh air
- How it affects your day – e.g. afraid to walk alone, have to rest in the afternoon



It is important to recognise signs of infection and to report any suspected infections to your healthcare team immediately, even if this is out of hours of your usual clinic times. Signs of infection can include raised temperature, chills and sweating, soreness or redness.



If you have any questions about your symptoms and side effects call the **Myeloma Infoline** on **0800 557 3332** or email them to **AskTheNurse@myeloma.org.uk**.





Other symptoms and side effects

Date	Time	Symptom/Side effect
How it feels		
How long it lasts		
What eases it		
Impact on your day		

Date	Time	Symptom/Side effect
How it feels		
How long it lasts		
What eases it		
Impact on your day		

Date	Time	Symptom/Side effect
How it feels		
How long it lasts		
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Impact on your day		



Other symptoms and side effects

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How it feels		
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How it feels		
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What eases it		
Impact on your day		



Questions and notes





Questions and notes



After receiving your myeloma diagnosis, you will undoubtedly have many questions about myeloma and its complications, treatment and how your diagnosis is going to impact on your life.



After and in between your appointments new questions might come to mind. Use this section to make a note of any questions you have for your healthcare team and any other points to remember.



Some common questions are listed in this section that may prompt further questions of your own.

You can also contact the **Myeloma Infoline** on **0800 980 3332** to speak to one of our Myeloma Information Specialists about your myeloma.



Alternatively, you can email any questions you have to **AskTheNurse@myeloma.org.uk**.



Questions you may want to ask your healthcare team

After diagnosis

- ☐ What tests will I need to have and when?
- ☐ How long will I have to wait for results and how will I be given them?
- ☐ Are my bones affected?
- ☐ Are my kidneys affected?
- ☐ Who should I contact when I have questions?
- ☐ Do you have any information I can take home?
- ☐ What help and support is available outside of the hospital?
- ☐ What can be done for the symptoms I have now?

Tests and treatment

- ☐ Should I avoid alcohol, certain foods, or activities like driving while on treatment?
- ☐ Will I have to pay for my prescriptions?
- ☐ Where can I get a prescription exemption form?
- ☐ Will I need to have tests and treatment? If so, when?
- ☐ What are my treatment choices?
- ☐ What would happen if I don't have treatment?
- ☐ How is the treatment given, how long will it take?
- ☐ What are the side effects of the treatment?
- ☐ Is the treatment part of a clinical trial?
- ☐ Can treatment affect my fertility?
- ☐ Can I carry on with work/normal activities (walking, lifting, socialising, having sex) whilst I am receiving treatment?
- ☐ Will I need to change my diet?
- ☐ Can you give me information about the treatment?
- ☐ Should someone come with me when I get the treatment, or the test results?

After treatment

- ☐ How soon will I be able to go back to work or go on a holiday?
- ☐ How often should I have a check up or blood test?
- ☐ Will I receive any other treatments such as bisphosphonates and maintenance treatments?
- ☐ Can I exercise?
- ☐ Can I eat normally?
- ☐ How will I know if the myeloma has come back?

Practical and financial support

- ☐ Where can I find information about finance/insurance, social services, occupational therapy, counselling, etc?
- ☐ Can I use complementary therapies?
- ☐ How do I organise transport to the hospital?



This section is yours to use however you find most helpful. You can use this space to write any questions or concerns you would like to discuss with your healthcare team.



Questions and notes



Questions and notes





Questions and notes



Help and support





Help and support



Myeloma UK exists to support everyone affected by myeloma.

We have a variety of different support and information services to help you live well. Get in contact to find out how we can support you.



There may also be support services available in your local area. Ask your healthcare team for details of local services.



Useful organisations

Carers UK

carersuk.org

0808 808 7777

Provides advice, information and support for carers.

Citizens Advice

citizensadvice.org.uk • adviceni.net

England: **0800 144 8848** • Wales: **0800 702 2020**

Scotland: **0800 028 1456** • Northern Ireland: **0800 915 4604**

Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.

Macmillan Cancer Support

macmillan.org.uk

0808 808 0000

Provides practical, medical and financial information and support to all cancer patients and their carers.

Maggie's

maggies.org

0300 123 1801

Provides free practical, emotional and social support to people with cancer and their family and friends.

Mind

mind.org.uk

0300 123 3393

Provides advice and support for anyone with mental health problems.

NHS 111 Service

nhs.uk/111

111

Call 111 when you need medical advice fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year.

Samaritans

samaritans.org

116 123

Listening and support free, 24 hours a day, to anyone who's struggling to cope.

We're here for everything a diagnosis of myeloma brings

Myeloma UK is here with information and support to help you and to connect you with others with shared experiences.



Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; with videos, news and articles to help you keep up to date and live well with myeloma.



Call our **Myeloma Infoline** on **0800 980 3332** for practical advice, emotional support and a listening ear.



Get answers to your questions by emailing our Myeloma Information Specialists at **AskTheNurse@myeloma.org.uk**.



Order or download our **information publications**, which cover all aspects of myeloma – call **0800 980 3332** or visit **myeloma.org.uk/publications**.



Learn about myeloma from experts and meet other patients at our **Infodays** and **Digital Infoday Sessions**.



Join a **Myeloma Support Group** to meet other people living with myeloma face to face or online.



Get matched up with a trained **Peer Buddy** for one-to-one support from someone with direct experience of myeloma.



Chat and share experiences with others affected by myeloma, including our peer volunteers, on the **Discussion Forum**.



MyelomaUK

Together, we are the cure

Every day thanks to our wonderful supporters, people with myeloma get the support, information and treatments they need.

 We've come a long way since we started. With life-extending treatments and care many people with myeloma now live longer, better lives. But when you're living with myeloma every day counts and we need to go further, faster.

All our charitable activity and support is funded by fundraising, voluntary donations, and gifts in wills. We couldn't do it without you, our supporters. Together, we are the cure.

Make a donation

You can donate online at **myeloma.org.uk/donate**

By phone on **0131 230 0429**

Or by posting a cheque payable to **Myeloma UK** to:

22 Logie Mill, Beaverbank Business Park, Edinburgh EH7 4HG

Fundraise

Fundraising is a positive way of making a difference and every pound helps. Fundraising is also a great way to raise awareness.

Leave a gift in your will

 Over a third of all our charitable activities are funded by gifts in wills. That's a third of Infoline calls, providing support and advice, a third of drug approval panels fighting for the next treatment and a third of research projects striving for the next breakthrough.



However you decide to raise funds, our team is here to support you. Contact us on **0131 230 0429**



or email **supportercare@myeloma.org.uk**

We appreciate your feedback



Please fill in a short online survey about our patient information at myeloma.org.uk/pifedback or email any comments to myelomauk@myeloma.org.uk





Your patient diary



We're here for everything
a diagnosis of myeloma brings

Get in touch to find out more about how we can support you

Call the Myeloma Infoline on

 **0800 980 3332**

Email Ask the Nurse at

 **AskTheNurse@myeloma.org.uk**

Visit our website at

 **myeloma.org.uk**

Myeloma UK

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